The following three dissertation chapters are manuscripts currently being prepared for submission to academic journals for publication. Upon submission, CIHR will be notified.

Chapter 5 Paper #1: Concept Mapping: Application of a Community-Based Methodology in three Urban Aboriginal Populations

Target Journal: American Indian Cultural Research Journal

Chapter 6 Paper #2: Using Respondent Driven Sampling to Unmask the Disparities in Social Determinants of Health for Urban First Nations People Living in Hamilton, Ontario

Target Journal: PLOS ONE

Chapter 7 Paper #3: Mental Health, Substance Use and Access to Emotional Supports among an Urban First Nations Population in Hamilton, Ontario

Target Journal: Transcultural Psychiatry

Our Health Counts – Unmasking Health and Social Disparities among Urban Aboriginal People in Ontario

by

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Abstract

In Canada, accessible and culturally relevant population health data for urban First Nations, Métis and Inuit people are almost non-existent. There is a need for Aboriginal community centric research and data systems, specifically in the area of mental health and substance misuse. The goal of this research was to address these knowledge gaps. The three linked studies being presented were nested in the Our Health Counts (OHC) project, a multi-partnership study aimed at developing a baseline population health database for urban Aboriginal people living in Ontario.

In the first study, concept mapping was used to engage urban Aboriginal stakeholders from three culturally diverse communities in identifying health priorities. After completing brainstorming, sorting and rating, and map interpretation sessions, three unique community specific maps emerged. Map clusters and their ratings reflected First Nations, Inuit, and Métis understandings of health. Concept mapping encouraged community participation and informed the development of three health assessment surveys.

The second study generated a representative sample of First Nations adults and children living in Hamilton, Ontario by utilizing Respondent Driven Sampling (RDS), a modified chain-referral sampling approach. Population estimates were generated for household and personal income, mobility, over-crowding and food availability. Results revealed striking disparities in social determinants of health between First Nations and the general population.

The third study used the RDS generated sample to examine mental health and substance misuse among First Nations adults living in Hamilton. Prevalence estimates were generated for diagnosis and treatment of a mental illness, depression, anxiety, post-traumatic stress disorder (PTSD), suicide, alcohol and substance misuse, and access to emotional supports. Findings indicated that First Nations adults living in Hamilton experience a disproportionate burden of mental health and substance misuse challenges.

The three linked studies make innovative contributions to Aboriginal health research. Results clearly exemplify the effective application of community-based research methods that are grounded in local knowledge and built on existing community strengths and capacities. Representative population health data for urban First Nations will contribute to current deficiencies in health information; will shape policy and programming priorities as well as future research directions, particularly with respect to health and social disparities among this population.

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Dedication

For my sons

David Fernando and Mateo Simon, who we welcomed in the midst of this journey and who keep life grounded and upside down all at the same time…

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Chapter 1
Introduction

In Canada, population health outcomes data on First Nations, Métis and Inuit populations living in urban areas are very limited. While census data do exist, there are serious deficits in population health measures. This is primarily due to the inability of Ontario's current health information system to properly identify urban Aboriginal[1] individuals in its health datasets and overall methodological flaws with sampling frames and resulting non-random study populations. In addition, there is an urgent need for more community centric research and data systems and measures that build on the strengths and priorities of Aboriginal communities. Through the application of community-based research (CBR) methods, the overall goal of the Our Health Counts (OHC) project was to generate useful and culturally relevant population health data for urban Aboriginal people in Ontario. In addition, a focused analysis of emotional and mental health outcomes was carried out in response to community concerns and top health priorities.

1   Objectives

Specifically, the overall objectives of this research were as follows:

1. To identify current health priorities of three diverse urban Aboriginal populations in Ontario through concept mapping in order to inform unique First Nations, Inuit and Métis health assessment survey tools.

2. To recruit a representative sample of urban First Nations people living in Hamilton, Ontario using respondent driven sampling (RDS) and to generate population proportion estimates for social determinants of health.

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[1] Aboriginal people" is a collective name for all of the original peoples of Canada and their descendants. The *Constitution Act* of 1982 specifies that the Aboriginal Peoples in Canada consist of three groups: Indians, Inuit and Métis. The term First Nations came into common use in the 1970s to replace Indian, which some people found offensive. Despite its widespread use, there is no legal definition for this term in Canada. In the United States, the term "Native American" is used to represent Indigenous peoples from North America, including Mexico. For alignment with the US Constitution and to ensure policy implications, the term "American Indian" is still used for Indigenous populations living within US borders, particularly the lower 48 states and parts of Alaska. "Indigenous" is a term used in the international context.

3. To generate prevalence estimates for mental health disorders, substance misuse and access to emotional supports among urban First Nations adults living in Hamilton, Ontario.

2 Organization of Thesis

This paper-based thesis begins with a literature review, which provides an overview of existing population health data, explores several of the fundamental social determinants of health impacting the mental health of Indigenous people and highlights relevant existing models of mental health care and service delivery.   Chapter 3 presents an exploration of several key theoretical and methodological approaches to research in this area. In Chapter 4, I describe the research setting and provide the broader context of the Our Health Counts project. Chapters 5 to 7 are the manuscripts for Objectives 1 to 3 in that order. In Chapter 8, I summarize the results, discuss strengths and limitations of the research and highlight future research implications.

Chapter 2 Literature Review

3   The Canadian Urban Aboriginal Landscape

According to the 2006 Census, over 60% (150,570 people) of Ontario's First Nations, Inuit, and Métis populations live in urban areas. In Canada, nearly seven out of ten Métis live in urban areas and about three out of every four people in the off-reserve First Nations population live in urban areas (Statistics Canada, 2008). In other words, the most urbanized groups are non-status[2] Indians and Métis with 73% and 69%, respectively living in urban areas (Norris M.J. & Clatworthy S., 2003). Aboriginal communities have often been dislocated from their original homelands and may constitute diasporic, heterogeneous communities in urban areas (Canadian Institute for Health Research (CIHR), 20097). Specifically, an increasing number of First Nations are moving to urban centres to seek better housing, employment and health care (National Aboriginal Health Organization (NAHO), 2003). We do know from the Canadian Census that First Nations, Inuit, and Métis populations experience ongoing disparities in social determinants of health such as income insecurity, unemployment, low levels of education, decreased food availability, and inadequate housing compared to non-Aboriginal Canadians and that these disparities are exacerbated with urban residence (Statistics Canada, 2008).

Using data from the 1996 census and the 1991 Aboriginal People's Survey, Norris and Clatworthy at Indian and Northern Affairs Canada analyzed Aboriginal migration and mobility within Canada and found that about 70% of Aboriginal residents in large urban areas had changed residences between 1991 and 1996, with more than 45% moving within the same community. More specifically, the off-reserve registered Indian populations were the most mobile as compared to Non-Status Indians, Métis and Inuit. According to Norris and Clatworthy, significantly higher Aboriginal mobility as compared to the general population can be explained by various "push and pull" factors between reserve and non-reserve Aboriginal communities and cities (Norris M.J. et al., 2003). Major reasons for migration included family

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[2] An individual recognized by the federal government as being registered under the *Indian Act* is referred to as a Registered Indian (commonly referred to as a Status Indian)."Non-status Indians" commonly refers to people who identify themselves as Indians but who are not entitled to registration on the Indian Register pursuant to the *Indian Act*. Some of them may be members of a First Nation. (Aboriginal Affairs and Northern Development)

and housing (regardless of destination), education (when leaving reserve) and employment (moves between urban communities) (Statistics Canada, 1993; Norris M.J. et al., 2003; Statistics Canada, 1998). The urban Aboriginal population in Canada has been characterized by family instability and high proportions of female lone-parent families; low income and economic marginalization; and high crime rates and victimization (ibid). It has been suggested that such challenges of urban living can lead to weak social ties and cohesion in neighborhoods and communities, which in turn can impact well-being and mental health and can perpetuate continued cycles of migration and mobility (ibid).

In addition to these social disparities, there are also political issues that directly impact Canada's urban Aboriginal peoples. Policy analyst Calvin Hanselmann describes this political climate:

> Canadian governments have historically been hesitant to create policies specific to urban Aboriginal people. Much of this hesitancy is related to disagreements over the unclear and controversial question of legislative authority, and therefore responsibility, for urban Aboriginal people. Whereas the Constitution clearly accords exclusive legislative authority for "Indians, and Lands reserved for Indians" to the federal Parliament (Constitution Act, 1867, s. 91(24)), authority and responsibility for other Aboriginal people is subject to disagreement…As a result, the federal government has traditionally focused its attention towards on-reserve status Indians and, in a policy sense, has largely ignored Aboriginal people living off reserves, including urban Aboriginal people (Hanselmann C., 2001).

Hanselmann explains that given the historical role of the federal government and its responsibility for Aboriginal people, provincial governments have been reluctant to take action, resulting in what the Royal Commission on Aboriginal Peoples has called a "policy vacuum" (Indian and Northern Affairs Canada, 1996). Accountability now often falls in the hands of municipal governments who frequently lack capacity and resources to effectively meet the needs of urban Aboriginal people (Hanselmann C., 2001). As Hansemann concludes, "The outcome of this policy void has been that urban Aboriginal people have largely fallen through the cracks. The Royal Commission on Aboriginal Peoples stated that "[m]any called this the most critical issue facing urban Aboriginal people" (Indian and Northern Affairs Canada, 1996).

Health care services continue to be provided by the Canadian federal government to people living on reserve and in remote communities. These services are a treaty-based responsibility. In 1974, the government initiated the "Indian Health Policy", now named the Health Transfer Policy, which does not recognize health as an Aboriginal treaty right and therefore maintains a pre-existing dependent relationship between First Nations people and the state. Aboriginal people living in urban centres in Canada (of which there is a growing number) are excluded from many of the benefits offered by the First Nations and Inuit Health Branch of Health Canada and the health status of those living off reserve has been largely ignored (McCue D. & Wigmore M., 1990).

4   Population Health Data

In Canada, population health outcomes data on First Nations, Métis and Inuit populations living in urban areas are very limited. While census data do exist and highlight social determinants of health for these populations, there are serious deficits in population health measures. Some of the reasons behind this deficiency are due to limitations in the current health information system and data collection processes with respect to Aboriginal peoples. For example, a respectful, systematic or consistent mechanism for individuals to self-identify as First Nations, Métis or Inuit ethnicity in Canadian population surveys does not exist. Sampling frames are often biased and comprise non-random subpopulations such as program/service client lists, membership lists, and Métis registry. When urban Aboriginal people have been included in census based national surveys (such as the Canadian Community Health Survey) these surveys are underpowered and often First Nations, Inuit, and Métis data cannot be successfully disaggregated (Smylie J. et al., 2010; Smylie J., Lofters A., Firestone M., & O'Campo P., 2011b; Smylie J., Anderson I., Ratima M., Crengle S., & Anderson M., 2006b). Additionally, studies based on Census data show that a significant number of Aboriginal people move from rural and reserve areas to cities, and back and forth as well as within and among cities. This mobility makes it difficult to get a firm count of the Aboriginal population of a city (Graham K.A. & Peters E.J., 2002). At the national level, the continued inability to identify all three of Canada's Aboriginal Peoples in healthcare databases leads to very poor coverage of Canada's Aboriginal population, with a specific paucity of health information for non-registered First Nations, Métis, and Inuit Peoples living in urban areas. Provincial and territorial systems generally do not collect ethnic specific utilization data, and their ethnic flags for vital statistics are inconsistent or absent

(Anderson M. et al., 2006). The Conservative government's recent decision to cancel the long form census will only widen this knowledge gap (Collier R., 2010).

4.1 Representation of Aboriginal Populations in Research Literature

Recently, the research and knowledge gaps in Canadian Aboriginal health have been called into question by several authors. A literature review of indexed articles in Medline revealed that research conducted among Aboriginal populations in Canada is severely lacking in Métis specific efforts, is limited in its coverage of urban or off-reserve populations as well as women and children and a large proportion of the research focuses on environmental health risks and genetics as opposed to other health determinants (Young BMJ 2003). Another literature review conducted by Wilson and Young was aimed at determining if the published literature in this area reflects the diversity of Aboriginal people in Canada. Again, the results show an under-representation of Métis and urban Aboriginal populations and focus primarily on health status, with a particular emphasis on chronic disease and lifestyle behaviours (Wilson and Young 2008). In addition, authors found very few articles examined traditional approaches to healing or access to traditional medicines and a small number of articles reflected community-based approaches to research (ibid). In response to the findings of such reviews and in order to assess the trends in Métis-related health research, Kumar et al. performed the first ever Métis-specific systematic health review and found that the majority of articles across three decades were pan-Aboriginal without a specific breakdown of findings for Métis people and for a large number of articles, the quality of data were moderate or low (Kumar et al. 2012). Furthermore, while Kumar et al. did observe increased attention to chronic disease (namely diabetes) and diet/nutrition, there remain large gaps in coverage of communicable diseases, premature mortality, as well as access to appropriate health care and the unique experiences that may impact the health and well-being of Métis people (ibid).

4.2 Mental Health

Not surprisingly, limited health information translates into very little Canadian Aboriginal mental health data. Prevalence rates of specific psychiatric disorders, diagnosed using culturally validated measures among Aboriginal people are almost non-existent. Most of the available data focus on First Nations and Inuit populations, as there is an almost total lack of

national Métis-specific health information at present. Existing prevalence data are crude and generally based on service utilization or clinic records, which produces gross underestimates, as many Aboriginal people do not utilize mainstream services (Kirmayer L.J., Brass G.M., & Tait C.L., 2000). There are however, several community surveys that were conducted in Canada and the United States, which have generated a wide range of prevalence rates of psychiatric disorders. This breadth of data is a result of both existing population differences as well as methodological challenges with diagnostic tools and symptom assessments (Kirmayer L.J., Tait C.L., & Simpson C., 2009). Results from the first large-scale epidemiological survey of 2 Native American tribes living on rural Indian reservations in the United States showed that overall rates of psychiatric disorders were comparable to the general U.S. population, however rates of post-traumatic stress disorder (PTSD) and alcohol dependence were higher (Beals J., Manson S.P., Mitchell C.M., Spicer P., & AI-SUPERPFP Team, 2003; Beals J. et al., 2005). In 1997, the First Nations and Inuit Regional Longitudinal Health Survey, which includes on-reserve and mostly non-urban populations, reported that about 18% of on-reserve First Nation and Inuit adult populations surveyed met the criteria for major depression; 27% reported problems with alcohol; 34% reported sexual abuse during childhood; and 15% attempted suicide at some time in their lives (First Nations Centre National Aboriginal Health Organization, 2004). Results from the 2002 RHS indicated that 30.1% of respondents had experienced a time when they felt sad, blue or depressed for two weeks or more in a row, 30.9% reported having suicidal thoughts over their lifetime, and 15.8% reported having attempted suicide at least once in their lifetime (Assembly of First Nations, 2007b). According to the 2000/2001 Canadian Community Health survey, 13.2% of the off-reserve Aboriginal population had experienced a major depressive episode in the past year, a number 1.8 times higher than the non-Aboriginal population (Tjepkema M., 2002).

Suicide rates among Aboriginal people in Canada are alarmingly high. Although there are enormous variations across communities, bands, and nations, the overall suicide rate among First Nation communities is about twice that of the total Canadian population; the rate among Inuit is 6 to 11 times higher than the general population (Aboriginal Healing Foundation, 2007; Health Canada, 2001b). A recent study published by Statistics Canada reported that between 2004-2008, children and teenagers in Inuit Nunangat were more than 30 times as likely to die from suicide as those in the rest of Canada (Oliver L.N., Peters P.A., & Kohen D.E., 2012). Marked differences in rates, even in the same geographical area has been noted by Chandler and Lalonde

who found that among British Columbia's some 200 Aboriginal communities, there were populations with suicide rates 800 times that of the National average, while for other communities, suicide is virtually unknown (Chandler M.J. & Lalonde C., 1998). As Kirmayer et al. explain in the Aboriginal Healing Foundation Report on Suicide, it is not only the seriousness of suicide itself that causes alarm, but also its ripple effects on the community:

> Suicide is just one indicator of distress in communities. For every suicide there may be many more people suffering from depression, anxiety, and other feelings of entrapment, powerlessness, and despair. At the same time, every suicide has a wide impact affecting many people—family, loved ones, and peers who find echoes of their own predicament, and who sometimes may be prompted to consider suicide themselves in response to the event. The circle of loss, grief, and mourning after suicide spreads outward in the community. In small Aboriginal communities where many people are related, and where many people face similar histories of personal and collective adversity, the impact of suicide may be especially widespread and severe (Aboriginal Healing Foundation, 2007).

4.3 Concurrent Disorders

In many populations, both Indigenous and non-Indigenous, substance use problems and mental health disorders often occur together. Concurrent or dual disorders are receiving increased recognition in both the addictions and mental health fields, resulting in the emergence of integrated, multi-disciplinary models of care, particularly in urban, community-based contexts (O'Campo P. et al., 2009). Nonetheless, there is a large knowledge and service gap for concurrent disorder treatment in this context and an even greater dearth of evidence for Aboriginal populations (ibid). For example, a National Program Inventory on Concurrent Mental Health and Substance Use Disorders was compiled in 2001 to provide a system-level snapshot of specialized programs for people with concurrent disorders across Canada. Questionnaires were sent to all agencies across Canada who were identified in the Canadian Centre on Substance Abuse's (CCSA) national directory as providing services to individuals with concurrent disorders and of the 37 who responded, only 2 of the programs offered services specifically to Aboriginal individuals (youth and adults) (Health Canada, 2001a). Not surprisingly, empirical evidence is very limited. Recently, Bonnie Duran et al. conducted a study with 234 American Indian/Alaska Native (AI/AN) women using the outpatient and urgent care

clinics of the Indian Health Services hospital in Albuquerque, New Mexico. The study administered the Composite International Diagnostic Interview (CIDI) to determine mental disorder prevalence estimates.   Study results revealed a high comorbidity between substance-related disorders and mood and anxiety disorders. Among the women with any lifetime substance-related disorder, 74% had a lifetime anxiety disorder and 57% had a lifetime mood disorder. Of those women with any substance use disorder, 72% reported an anxiety disorder and 39% reported a mood disorder within the past year (Duran B. et al., 2004). Despite a lack of rigorous evidence, there are descriptive studies of programs, which are showing promise, particularly in Native American communities.   Urban services targeting Native Americans with concurrent disorders encompass some or all of the following elements: options for both Western therapy and/or traditional healing practices; a holistic approach to physical, mental, emotional, and spiritual wellness; recognition of the impact of past and current trauma; and involvement of peer-based models of care and recovery (Brave Heart M.Y.H., 2004; Nebelkopf E. & King J., 2004; Nebelkopf E. & Penagos M., 2005).

5   Qualitative Evidence

Qualitative and ethnographic research involving narratives and life histories reveal the individual and shared experiences of historical and current forced assimilation, loss of identity and isolation that Aboriginal people in different communities across Canada are facing. In particular, there is a growing body of literature that looks at the devastating impacts of the residential school system in Canada. These documents describe the ongoing psychological and transgenerational effects of residential schools, which were mandated by the Canadian government from 1879 to 1973, during which time, around 100,000, mainly First Nations children were taken from their homes and communities and subjected to a strict regime that denied them of any cultural expression and heritage. In addition to the suppression of culture and language, there was also widespread sexual, emotional and physical abuse (Kirmayer L.J., Simpson C., & Cargo M., 2003; Aboriginal Healing Foundation, 2006).

Qualitative research has begun to uncover some of lasting health impacts of the residential schools. For example, a qualitative study exploring the experiences of close to a hundred residential school survivors in one region of British Columbia found that 93% of former residents reported extreme loneliness and feelings of abandonment, 91% reported

loss/suppression of language and culture, 92% had witnessed abuse of other residents, 90% reported having been abused in one or more ways (e.g., sexually, physically, emotionally), 76% reported having lost their self-respect or feeling inferior, and 84% reported problems with relationships, family, parenting, and communication (Nuu-chah-nulth Tribal Council, 1996).

In Vancouver's downtown east side, HIV rates are about twice as high among both male and female Aboriginal intravenous drug users compared to non-Aboriginals. Aboriginal women are seroconverting to positive HIV status at rates that exceed any other Vancouver or Canadian population (Spittal P.M., 2002). The Health and Home Project created a safe space for both Aboriginal and non-Aboriginal women in the downtown east side to share their stories. Dara Culhane, professor of Anthropology and principle investigator collects and shares Aboriginal women's autobiographies as a way to demonstrate how health effects of social exclusion and colonialism are embodied and even resisted among Aboriginal women living with addictions and involved in sex work (Culhane D., 2009; Culhane D., 2003). Culhane draws from personal stories as important sources of recommendations and direction for providers and policy makers alike. Some common themes in the women's stories included the need for programs with more instrumental support such as housing, education and employment, the importance of building strong support networks, access to safe housing as protection from interpersonal violence, a desire to reconnect with children, families and communities and asserting pride in Aboriginal identity as part of the healing process (Culhane D., 2009). As many Canadian and American authors have concluded, the life histories of those impacted by the residential school system and other forms of oppression and social exclusion indicate many potential connections to individual, family and community level mental health issues (Aboriginal Healing Foundation, 2007; Fournier S. & Crey E., 1997; Nuu-chah-nulth Tribal Council, 1996; Aboriginal Health Foundation, Wesley-Esquimaux C.C., & Smolewski M., 2004)

6   Social Determinants of Health

Recognized internationally as an essential lens through which we establish and explain health issues, social determinants of health are defined by the World Health Organization (WHO) as: the conditions in which people are born, grow, live, work and age, including the health system. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels, which are themselves influenced by policy choices

(World Health Organization, 2010). Health inequities are mostly shaped by social determinants of health. For Aboriginal people, ill health is directly linked to social determinants of health including colonization, cultural suppression, family and community dislocation, chronic unemployment, poverty, lower education attainment, and unhealthy environments (National Aboriginal Health Organization (NAHO), 2003). In 2007, at the International Symposium on the Social Determinants of Indigenous Health, colonization was identified as an important underlying determinant of health that continues to impact health and well-being (International Symposium on the Social Determinants of Indigenous Health, 2007). Other fundamental social determinants highlighted at the symposium were the severance of ties of Indigenous people to their land, the related weakening of cultural practices, poverty and economic inequality and consequently, overall poor health (ibid). In Canada, The Royal Commission on Aboriginal Peoples (RCAP) also identified poverty, despair, poor housing and political alienation as some of the root causes for many of the traumatic mental health problems prevalent in aboriginal communities (Smye V. & Browne A., 2002; O'Neil J.D., 1993). Clearly, both historical and present day experiences need to be addressed when exploring mental health issues in this population. As stated by Smye and Brown, both professors of nursing at the University of British Columbia, "the dominant mental health problems for aboriginal people are social in nature, rooted in a long history of oppression and current social conditions." (Smye V. et al., 2002).

In alignment with Charlotte Loppie Reading and Fred Wein's work, across the lifespan, physical, emotional, mental and spiritual dimensions of Aboriginal peoples' health is influenced by a broad range of distinct proximal, intermediate and distal social determinants of health (Loppie Reading C. & Wien F., 2009). Clearly, in the context of Aboriginal mental health, we need to look at both individual-level factors and larger social or ecological constructs impacting this population. Given the profound impact of colonization as well as the ongoing isolation and marginalization of Aboriginal people, I will first focus on these distal social determinants of health and then will explore the importance of culture and community as potential mediating factors for achieving health and well-being in an Indigenous context.

6.1   Historical Trauma

The complexity and layered impacts of colonization on the well-being of Indigenous people have been examined by several Indigenous scholars. Duran and Duran refer to the community trauma and pain experienced by American Indians/Alaska Natives (AI/ANs) as a "soul wound", the direct result of the genocidal effects of colonization (Duran E. & Duran B., 1995). Native American professor of social work Maria Yellow Horse Brave Heart and Lemyra De Bruyn at the Native Diabetes Wellness Program (Centers for Disease Control) describe this chronic trauma from the loss of lives, land and culture across generations as "historical unresolved grief" (Brave Heart M.Y.H. & DeBruyn L., 1998). Navajo psychologist Rose Clark and Ojibwe/Oneida psychologist Antony Stately clearly summarize the concept of traumatic loss: The current generations of American Indians face layers of repetitive traumatic losses that are physical, cultural and spiritual in nature. These multiple layers of repetitive loss, in addition to the major traumas of the past, contribute to the pain, psychological numbing, and destructive coping that can best be described as a chronic stress disorder at a community level (Clark R.L. & Stately A., 2004).

While there are challenges with defining and evaluating historical trauma, there have been attempts to measure these constructs and generate some empirical evidence to support what has been observed for the past several decades in many communities. Through a series of focus groups with Native American elders both on and off reserve in the Midwestern United States, Whitbeck and colleagues have developed two scales to measure historical loss: The Historical Loss Scale and The Historical Loss Associated Symptoms Scale. The scales have been administered in the first wave of a longitudinal study of American Indian families with children aged 10 through 12 years on two reservations in the upper Midwestern U.S. and two Canadian reserves in Ontario (Whitbeck L.B., Adams G.W., Hoyt D.R., & Chen X., 2004). The perceived historical losses scales included some of the following: loss of land, loss of traditional language, loss of traditional spirituality, loss of respect for elders and loss due to early deaths. Preliminary results indicated elevated prevalence of historical trauma among the parents included in the study and revealed an association between historical losses and emotional stress, specifically anger/avoidance and anxiety/depression (ibid). While there is still more to learn about this construct and the mechanisms through which it manifests, follow-up work by the same authors has produced additional support for the validity and cultural appropriateness of the perceived

historical loss measure (Whitbeck L.B., Walls M.L., Johnson K.D., Morrisseau A.D., & McDougall C.M., 2009; Whitbeck L.B., Chen X., Hoyt D.R., & Adams G.W., 2004).

The Cedar Project is a community based research project that addresses exposure to HIV and Hepatitis C among Aboriginal youth who use illicit drugs in three cities in British Columbia. In a recent publication about the project, historical trauma was defined as having at least one parent who attended a residential school and/or ever having been taken from biological parents into care. Authors report significant univariate associations between having at least one parent who attended residential school and involvement in the child welfare system with sexual abuse among Cedar Project participants. While controlling for sociodemographic and historical trauma variables, survivors of childhood sexual abuse in this cohort were found to be at significantly higher risk of serious negative health outcomes (For the Cedar Project Partnership et al., 2008). Recently, the first empirical study using a representative Aboriginal population sample explored the link between direct or indirect exposure to Canada's residential school system and a lifetime history of abuse and/or suicide behaviour histories (Elias B. et al., 2012). Using data from the Manitoba First Nation Regional Adult Health Survey conducted in 2002/2003, authors found that among residential school attendees, negative experiences in residential school were associated with a history of abuse, and that, particularly for younger attendees, this history was associated with a history of suicidal thoughts (ibid).

Dr. Peter Menzies, clinical director for Aboriginal services at CAMH published a paper on his work aimed at identifying the indicators of intergenerational trauma in a sample of Aboriginal homeless men (Menzies P., 2006). Through semi-structured interviews with 16 men using services at Na-Me-Res, a Native men's residence in Toronto, Menzies identified indicators of intergenerational trauma at the individual, family, community and national level. Menzies' data revealed how social policies, including the Indian Act, child welfare legislation and the residential school system have had a colonizing impact that has stripped away traditional values and social cohesion for the men interviewed. Many individuals experience what Menzies refers to as "social anomie" or a feeling of disconnection from a particular cultural group, which has "left the Aboriginal nation in a similar state - unable to draw upon common bonds to bring individuals, families, and communities together"(Menzies P., 2006).

A history of forced assimilation in Canada has had a serious impact on individual factors such as identity and mental health as well as on the dynamics and overall structure of communities, bands and nations (Kirmayer L.J. et al., 2003). It must be recognized that the mental health consequences of historic events and policies have been different for First Nations, Métis and Inuit and between groups living on and off-reserve in Canada and in the United States. The existing literature speaks to the need for future efforts to highlight the experiences and knowledge from distinct communities. More work is also needed to develop and employ appropriate measures and indicators of historical trauma in Aboriginal contexts.

6.2   Dislocation and Isolation

Dislocation and isolation can be conceptualized in a variety of different contexts and can take on different meanings. On one level, there is dislocation in a physical or geographical sense. It can also mean loss of culture and community, as well as marginalization and exclusion from decision-making at different social and political levels of society.

Historically, the idea that Aboriginal people were far away and isolated maintained the idea of the 'other', an unreachable group who were not integrated members of mainstream society. History professor at the University of Winnipeg Mary Jane McCallum has critiqued the isolation discourse as it was portrayed with respect to Aboriginal health in papers published by reputable Canadian medical journals between 1910 and 1970. She explains:

> Isolation was a metonym for cultural difference, and overcoming the difficulties of transportation and communication was intimately tied to a broader project of assimilation. The location of Aboriginal health on the outer reaches of the nation ultimately served the broader project of colonization, as articles showcased the role that Indian Health Services and its officers played in mapping a healthy Canadian state…A discourse on isolation permitted medical and public health professionals to impose notions of space, race, health and medicine on Aboriginal people while they ignored the real impacts of colonization on their health (McCallum M.J., 2005).

Although McCallum's analysis does not incorporate the last several decades of publications in this area, many of these ideas continue to persist today.   With so much of the Aboriginal

community now living in urban centres, geographical remoteness no longer serves as a justification for isolation and yet, other forms of social exclusion have taken its place.

In Chapter 7 of his book entitled, 'Revenge of the Windigo', Canadian anthropologist, J.B. Waldram focuses on depression among Aboriginal people. He maintains that depression and suicide research clearly indicates that Aboriginal people suffer from high rates of both and the explanation for this generally falls into two schools of thought. The first relates to social disorganization, acculturation and alienation from society. Rooted in several sociological paradigms, this explanation upholds that communities were relatively free from pathologies until contamination from industrialized nations occurred and all the cultural, social and economic changes that emerged from this contact (Waldram J.B., 2004). In this school of thought, scholars have looked at depression from being caught between two worlds-'dependence depression'-as a result of a dependence on the Federal government and an almost 'adult-child' metaphor, loss of one's tribe and family members (ibid). The second school of thought proposes that specific Aboriginal cultures have predisposed individuals to experience certain pathologies and not others and that contemporary psychopathology must be understood within the context of continuing cultural traditions and adaptation to new circumstances not severed ones of the past (Waldram J.B., 2004). This argument recognizes that culture did not cease to be important to Aboriginal peoples with the arrival of the Europeans.

While there is limited empirical evidence supporting the link between dislocation of Indigenous people to inferior mental health and wellbeing, there are some strong data emerging from Australia. Using data from the Western Australian Aboriginal Child Health Survey (WAACHS) that was undertaken from 2000 to 2002, Silburn et al. published a report entitled, The intergenerational effects of forced separation on the social and emotional wellbeing of Aboriginal children and young people (Silburn S.R. et al., 2006). In this paper, authors reported that after adjusting for age, sex and level of relative geographic isolation, Aboriginal caregivers of Aboriginal children who had been forcibly separated from their natural family were 1.5 times more likely to have had contact with Mental Health Services in Western Australia and1.61 times more likely to report the overuse of alcohol caused problems in the household. Additionally, 32.7% of children whose primary caregiver was forcibly separated from their natural family by a Mission, the government or welfare agency were at a significantly higher risk for emotional or behavioural difficulties compared to children whose caregivers were not forcibly separated from

their natural families and non-Aboriginal children in Western Australia (ibid).

6.3   Culture and Community

Social determinants of health and well-being for Indigenous populations are closely tied to culture and community. It has been proposed that service providers and policy analysts focus on medically defined mental health disorders, but also on the survival of Canadian Aboriginal communities. As Smye and Browne explain, "….this does not mean that aboriginal people live without schizophrenia, bipolar-disorder and other affective disorders and that these are of no concern to their communities, but that these disorders are considered less problematic in relation to community survival" (Smye V. et al., 2002)(pp.51-2). Related, is the idea of social integration and that the more collective needs are fulfilled, the healthier a community may be (Castellano M.B., 2000; Smylie J. et al., 2009). Community in the context of Aboriginal research constitutes a structure of support mechanisms that includes an individual's personal responsibility for the collective and, reciprocally, the collective's concern for individual existence (Kirmayer L.J. et al., 2000). Related, Aboriginal conceptions of community often encompass relationships in a very broad sense, including relationships of human, ecological and spiritual origins(Absolon K.E., 2010; Ermine W., 1995) .

Cultural loss has is also considered a significant determinant of health and well-being in the Aboriginal community. Positive cultural identity has been linked to resilience and healing in Aboriginal communities, triggering a call for the preservation of languages and a return to a more traditional way of life by Aboriginal community leaders (National Aboriginal Health Organization (NAHO), 2002). Alternative to Whitback's historical losses scale, within the resilience literature, concepts such as enculturation and cultural spiritual orientation have been explored as protective factors against substance abuse, suicide ideation and suicide attempts and depressive symptoms in Indigenous communities. Enculturation is defined as an ongoing process through which individuals gain knowledge and identity within their minority culture (Zimmerman M.A., Ramirez-Valles J., Washienko K.M., Walter B., & Dyer S., 1996). This construct is of particular value for Indigenous people who have historically been forced to deny and abandon their cultural identity. First Zimmerman and then Whitbeck have used similar measures of enculturation in their work with Native American populations in the Midwestern United states. Specifically, the measures address three components: cultural affinity (pride and

interest in Native American culture), cultural identity and involvement in cultural activities/spirituality. Overall, research outcomes have been mixed (Flemming J. & Ledogar R.J., 2008). In a few recent studies with Native American populations both on and off reserve, however, enculturation, measured using all three components appears to be protective against alcohol and other substance abuse and suicidal ideation (Yoder K.A., Whitbeck L.B., Hoyt D.R., & LaFromboise T., 2006). In Yoder's study of 212 American Indian youth living on or near three reservations in the upper Midwestern United States, enculturation was not significantly associated with current thoughts of suicide at the bivariate level, however it was found to be the second strongest predictor (after drug use) of suicidal ideation in the final multivariate model (ß= -0.20) (Yoder K.A. et al., 2006).

Community and cultural factors have emerged as important factors in studies on Inuit concepts of mental health and suicide. Specifically, researchers are starting to explore the relationship between the stresses of colonization and cultural discontinuity and rates of suicide and other indices of trauma (Kirmayer L.J. et al., 2000; Chandler M.J. et al., 1998). After decades of Aboriginal suicide research in British Columbia, Chandler and Lalonde have identified bands where suicide rates are well above the national average and other bands where suicide is non-existent (Chandler M.J. & Lalonde C., 2009). The more recent focus of their research has therefore been to identify and qualify what knowledge or cultural values one community experiencing wellness might offer another community currently in distress. This has led to the emergence of a developmental theory of individual and community level identity structure and resulting "proxy" variables that serve to characterize those communities more or less successful in understanding their past and taking control of their evolving future. The presence of factors such as evidence that bands have taken steps toward claiming aboriginal title to land, presence of self-governance, community control over health services and the establishment of official cultural facilities, were associated with lower levels of suicide (Chandler M.J. et al., 2009).

Many Aboriginal organizations recognize the importance of ''culture as intervention'' and support suicide intervention programming based upon histories of resilience and resistance (For the Cedar Project Partnership et al., 2008; Spittal P.M., Craib K.J., Teggee M., Moniruzzaman A., & Schechter M.T., 2007). Further investigation into the nature of communities, their response to the stresses of colonization and the mediating factors contributing

to high levels of stress and substance abuse is needed (Kirmayer L.J. et al., 2000; Chandler M.J. et al., 1998).

7   Existing Delivery Models of Mental Health Care

7.1   Biomedical vs. Traditional Models of Care

The current mental health service delivery model has strong psychiatry and biomedical traditions and is largely absent of Indigenous knowledge and experiences. The biomedical model targets the passive patient who requires some kind of intervention as opposed to a more holistic, Aboriginal model of wellness that involves the physical, emotional, spiritual and mental aspects of a person who is always in connection with his or her community and family (Adelson N., 2005). Mainstream biomedical healthcare as it has evolved in relation to Aboriginal communities has been heavily influenced by a century of internal colonial politics (ibid). Furthermore, the system itself is flawed with racist overtones and consists of providers who are trained to deliver services to the dominant population (Tang S.Y. & Browne A., 2008).

Several authors have described the limitations of the mainstream model of mental health care from an Indigenous perspective. For example, Kirmayer et al. explain, "Psychotherapy and other mental health interventions assume a particular cultural concept of the person, with associated values of individualism and self-efficacy which may not fit well with traditional Aboriginal cultural values…family and social network approaches that emphasize the relational self may be more consonant with Aboriginal culture, particularly if they are extended to incorporate some notion of the interconnectedness of person and environment" (Kirmayer L.J. et al., 2000). The authors also highlight the need to rethink the applicability of different modes of intervention from the perspective of local community values and aspirations. (Kirmayer L.J. et al., 2000; Trimble J.E., Manson S.M., Dinges N.G., & Medicine B., 1984).

Here in Canada, the diagnosis of mental illness and mental disorders of individuals are completed by physicians, psychiatrists, and other mental health professionals using the Diagnostic Statistical Manual – 4th Edition (DSM-IV-TR) developed by the American Psychiatric Association. The DSM has been in existence since 1952 and over the course of almost fifty years, has undergone five revisions, however it was not until the DSM-IV that culture and its impact on psychiatric diagnosis was acknowledged (Christensen M, 2001b).

Specifically, these changes include, cultural variation in 76 of the DSM disorders, an appendix of culture-bound syndromes such as "ghost sickness," an experience observed among certain American Indian groups and an appendix that includes a cultural case formulation outline that allows clinicians to provide details about the individual's cultural experiences (ibid). Through her exploration of a hypothetical case of an American Indian woman living on reserve who presents with a history of alcohol dependence and major depression, Christensen applies these tools in a comprehensive and meaningful way. For example, Christensen is able to conduct a psychiatric assessment through a cultural lens, exploring the individual's cultural identity including her loss of language and cultural practices, the meaning and severity of symptoms in relation to cultural norms, the cultural factors related to the psychosocial environment and the cultural elements between the individual and clinician (Christensen M, 2001a).

Even in light of Christensen's efforts, I am doubtful that such sensitivity and training is widespread in the clinical community, particularly among non-Indigenous practitioners who work in more mainstream institutions and in urban areas. The DSM and other diagnostic tools are overwhelmingly grounded in western science and based on a disease-oriented models, which cannot adequately capture the impact of historical, cumulative trauma that has occurred across generations (Brave Heart M.Y.H. et al., 1998).

7.2   Integration of Mainstream and Traditional Approaches

There exists a current gap in the literature describing and evaluating culturally based interventions and prevention strategies that consider Indigenous history and cultural values (Brave Heart M.Y.H., 2004). In addition, there is a tendency to marginalize traditional practices within the larger mental health care system. Notwithstanding, efforts are being made to identify processes that support integration of services and 'best practices' for Aboriginal mental health programs and services.

The body of literature on practices of traditional medicine in North America is in its early stages and most of what has been published is descriptive accounts of traditional healing experiences and the utilization patterns of traditional medicine by different population groups. There is little knowledge around the collaborative processes of integrating traditional and western medicine within a clinical setting and the impact of integrated models on Aboriginal communities and families. Maar and Shawande attempted to document this process in a health

centre setting on Manitoulin Island through a 10-year long case study of the healing services at Noojmowin Teg Health Access Centre and 17 in-depth interviews with service providers and clients at Manaamodzawin Noojmowin Teg Mental Health Services (Maar M.A. & Shawande M., 2010). The authors found several key elements that facilitated integration of Anishinabe healing and mainstream clinical services and resulted in positive experiences for clients: traditional healing protocols that were developed through community consensus and incorporated oral traditions and cultural values, on-going educational opportunities for Aboriginal and non-Aboriginal providers and community members, an interdisciplinary mental health team that included a traditional healing co-coordinator, and a focus on client choice related to services (ibid).

The Aboriginal Mental Health Committee in British Columbia have outlined several principles and values that are viewed as being key to the achievement of 'Best Practices' in Aboriginal mental health and wellness programming (Smye V & Mussell B., 2001). These elements include: holism/balance, client-focus, community/family centered, self-determination, co-reliance, comprehensiveness, integrated and coordinate, accessible, accountable, ethical, sustainable, humaneness, functional/practical and culturally safe/relevant. The report goes on to provide examples of what works in different program settings across Canada. One urban-based example is Anishnawbe Health Toronto (AHT), an accredited community health organization funded by the Ministry of Health and Long Term Care, whose mission is "to improve the health and well being of Aboriginal People in spirit, mind, emotion and body by providing Traditional Healing within a multi-disciplinary health care model" (Anishnawbe Health Toronto, 2010). The centre is dedicated to full recovery and well-being of the community by providing education and health promotion in areas such as STD/HIV prevention, nutrition and healthy lifestyle. AHT not only promotes traditional Aboriginal practices, but has affirmed and placed them at its core. Given the diversity of the Aboriginal population accessing services at AHT, care delivery is provided in Cree, Ojibway and English. AHT exposes its clients to a historical perspective and provides opportunities to learn about traditional teachings, healing and practices as way to shed light on current understandings of political, social and economic situations (Smye V et al., 2001; George P. & Nahwegahbow P., 1993)

Recently, a special issue of the Journal of Psychoactive Drugs explored evidence-based practices in substance abuse treatment and prevention practices that address historial contexts

and Native American ways of knowing (Cervantes T. et al., 2011). A ten-year review of the Holistic System of Care (HSOC) for Native Americans in an Urban Environment, based in the San Francisco Bay area highlighted the links between treatment, prevention and recovery in a holistic model and the importance of early intervention (Nebelkopf E. & Wright S., 2011). An evaluation of the HOSC provided preliminary evidence for the effectiveness of this model in significantly reducing substance use, increasing enrollement in school or a training program, a decrease in the number of reported arrests and a significant reduction in the rates of non-substance use-related depression, tension and anxiety (Nebelkopf E. et al., 2011; Wright S. et al., 2011). The HOSC is a recognized program model that empahsizes the important role of culture and culture connection/reconnection in addition to other mainstream methods (ibid).

8   Summation

This review of the literature has highlighted several key knowledge and research gaps: almost non-existent population-based data for urban Aboriginal people in Canada, the present disconnect between biomedical and mainstream concepts of health and Indigenous experiences, a lack of empirical evidence on existing mental health services targeting urban Aboriginal people and a lack of culturally grounded or validated measures for assessing or diagnosing mental health issues in this population.

Chapter 3 Theoretical Framework, Mixed Methods and
Community-Based Research

9   Framing of Aboriginal Health Research

Over the last several years, as the Indigenous research and academic community expands, there is a growing assertion of an Indigenous paradigm, guided by Indigenous knowledge and shaping current methodology and research endeavors. Wilson identifies four stages in the development of Indigenous research: the first is characterized by few Indigenous scholars working solely from within Western paradigms, the second and third stages move toward increased integration between Western and Indigenous paradigms and the fourth is more recent and involves Indigenous researchers illuminating their own worldview from an Indigenous perspective (Wilson S., 2003). In this section of the dissertation, I will describe some of the theoretical foundations and methodologies currently driving this process and will highlight contrasts and gaps between Indigenous ways of creating knowledge and those of more Western, Eurocentric origins.

10   Theoretical Perspectives

10.1 Postcolonial or Decolonizing Theory

Most simply, Postcolonialism encompasses a set of ideologies that centre on the direct impacts and aftermath of colonialism. Postcolonial theory is not only focused on an analysis of the legacy of colonialism, but also recognizes the continuation of colonial structures in contemporary society. While there are many important theorists who have produced work in this area over the past several decades, in the context of this thesis, I have elected to highlight Indigenous scholars from Australia and Canada who have examined post-colonial experiences from an Indigenous perspective. One such Canadian First Nations educator is Marie Battiste who distinguishes between Eurocentric notions of postcolonial theory and Indigenous postcolonial thought, maintaining that the latter is based on Indigenous experiences, acknowledging that colonial structures continue to persist, but can be resisted and healed through a commitment to Indigenous knowledge and its practice (Battiste M, 2000). Specifically, Battiste explains, "Postcolonial Indigenous thought is based on our pain and our experiences, and it refuses to allow others to appropriate this pain and these experiences…Indigenous scholarship,

along with research that requires moral dialogue and the participation of Indigenous communities, is the foundation for postcolonial transformation" (ibid).

Indigenous decolonization is a process by which Indigenous people come to understand the history of their colonization and its effects, rediscover traditional practices and values, cope with residual trauma, and face ongoing forms of oppression that continue to marginalize Indigenous people. Linda Tuhiwai Smith, a Maori professor of Indigenous Education at the University of Auckland in New Zealand emphasizes the importance of reclaiming history as a means to understanding the present as a critical facet of the decolonizing process. Smith believes that embodied in the revisiting of history is the understanding that colonialism persists combined with a process of creating alternative histories and knowledge, which in turn contributes to a theory that guides action. Specifically, "Telling out stories from the past, reclaiming the past, giving testimony to the injustices of the past are all strategies which are commonly employed by indigenous peoples struggling for justice." (Smith L.T., 1999). Likewise, Smylie et al. describe a decolonizing health research framework which recognizes the local diversity of Indigenous knowledge systems that existed prior to colonization, which were actively suppressed and denied and the continued negative impact of colonization on the health of Indigenous peoples (Smylie J. et al., 2009).

Research, for the most part is largely controlled and orchestrated by outsiders and thus has been associated with a loss of control and experiences of subjugation. In opposition to this research model, 'Indigentist' research is anti-colonial research, which counters colonizing methods and emanates from an Indigenous worldview. According to Australian Aborigine scholar Lester-Irabina Rigney, "The cultural assumptions throughout dominant epistemologies in Australia are oblivious of Indigenous traditions and concerns. The research academy and its epistemologies have been constructed essentially for and by non-Indigenous Australians…the process of racialization declared that my people's minds, intellects, knowledge, histories, and experiences were irrelevant." (Rigney, 1999). Drawing from Feminist critique and theory, Rigney proposes three guiding principles in 'Indigenist' research: resistance as the emancipatory imperative, political integrity, and privileging Indigenous voices. For Rigney, 'Indigenist' research is therefore a form of protest and liberation that cannot be isolated from the Australian political context and must embrace the lived experiences and history of Indigenous peoples (Rigney, 1999).

Similarly highlighted by Smith, the terms 'research' and 'problem' are closely linked for Indigenous peoples, such that, the word 'research' is believed to mean quite literally the continued construction of Indigenous peoples as the problem. Smith therefore calls for a 'decolonizing' of such epistemologies and methodologies, not a total rejection of all research and Western knowledge, but a process by which Indigenous peoples come to know theory and research from their own perspective, serving their own purposes (Smith L.T., 1999). By doing so, Indigenous people can reaffirm their own cultural values and knowledge system and thereby participate in their own liberation from oppression. Clearly, the rationale and principles underlying the development of Smith's and Rigney's theoretical frameworks in Australia are appropriate and relevant to the Canadian Aboriginal context. In 1991, the Canadian federal government initiated a commission to examine and report on the relationship between Aboriginal peoples and Canadian Society. Several years later in 1996, the government released its five-volume report known as the Royal Commission on Aboriginal Peoples, which contained analysis and recommendations for more equitable participation of Aboriginal people in Canadian life. One of the challenges facing Aboriginal people is that they must, "translate the well-honed critique of colonial institutions into initiatives that go beyond deconstruction of oppressive ideologies and practices to give expression to Aboriginal philosophies, world views, and social relation." (Castellano M.B., 2000). As Smylie et al. explain, in order to improve the health of Indigenous communities, the decolonizing process must involve, "a critical examination and dismantling of individual and systemic assumptions and power relationships, including the suppression of Indigenous systems of knowledge" (Smylie J. et al., 2009).

10.2 Relationality and Holistic Worldview

This theoretical approach is based on the premise that Indigenous thought is holistic, circular and relational and nothing is simply a cause and effect, but all factors are influences impacting other elements of the system as a whole (Ermine W., 1995; Colorado P., 1988; Cole A.L. & Knowles J.G., 2001). Cree community psychologist Shawn Wilson asserts that Indigenous thought and knowledge are reciprocal and interdependent and that Indigenous paradigms differ from Eurocentric positions in that they are built on, "The fundamental belief that knowledge is relational... It is with the cosmos, it is with the animals, with the plants, with the earth that we share this knowledge" (Wilson S., 2001). Similarly, Alfred Taiaiake, a Mohawk writer and professor, maintains that, contrary to Western materialism and the honouring of

individual autonomy, "Indigenous philosophies are premised on the belief that the human relationship to the earth is primarily one of partnership. The land was created by a power outside of human beings, and a just relationship to that power must respect the fact that human beings did not have a hand in making the earth…" (Taiaiake A., 2004). A holistic worldview therefore supports a balanced relationship between humans, the earth they inhabit and the spiritual world. Whereas in Western worldviews, knowledge exists outside of the self, for Indigenous people, it begins from within, while being, living and doing (Ermine W., 1995). In her dissertation, First Nations scholar Kathy Absolon explains that Indigenous knowledge comes from ancestral teachings that are spiritual and sacred in origin and exists in visions, dreams, ceremonies, songs and dances and prayers. It is not knowledge that comes solely from books, but is lived and experiential. Indigenous knowledge is cyclical as it follows the natural laws of creation and encompasses the past, present and future (Absolon K.E., 2008).

Aboriginal philosophy maintains that all things are in constant motion. As indicated by First Nations educator Leroy Little Bear, "All things are animate, imbued with spirit and in constant motion. In this realm of energy and spirit, interrelationships between all entities are of paramount importance and space is a more important referent than time" (Little Bear L., 2000). One must look at the holistic picture in order to see patterns and to understand (ibid). In the context of wellness and healing, balance and relationality has been described by First Nations scholar and Associate Dean for Indigenous Education at the University of British Columbia Jo-ann Archibald:

> First Nations philosophical concept of wholism often refers to inter-relatedness between the intellectual, spiritual (metaphysical values and beliefs and the Creator), emotional, and physical (body and behaviour/action) realms to form a whole healthy person. The development of wholism extends to and is mutually influenced by one's family, community, Band and Nation. The image of a circle is used by many First Nations peoples to symbolize wholeness, completeness, and ultimately wellness. The never ending circle also forms concentric circles to show synergistic influence and responsibility to the generations of Ancestors, the generations of today, and the generations yet to come. The animal/human kingdoms, the elements of Nature/land, and the Spirit World are an integral part of the concentric circles (Archibald J., 1997).

This focus on the integration of mind, body, emotions and spirit, can be situated within the Medicine Wheel philosophy, such that health and wellness in a person's life are achieved through the harmonious balance of these traits (McCabe G., 2008; Bopp M. & Bopp J., 2001). The Medicine Wheel, made up of four quadrants is configured as a circle. It can function as a framework for understanding the interconnectedness of the mind, body, emotions and spirit, however, it is also a process (healing), a ceremony (sweats, sharing circles) and teachings (a code for living), meaning it can represent a place, a time and a presence (ibid). The Medicine Wheel encourages internal dialogue and the integration of one's mind, body, emotions and spirit, which can facilitate healing and guidance for Aboriginal people and communities who have adopted a damaged self-identity as a result of colonization and continued social exclusion (McCabe G., 2008).

While, the Medicine Wheel philosophy embraces a cyclical and holistic worldview, Western theoretical approaches to understanding human behaviour and health are not able to capture the reciprocal, collective foundation of Indigenous knowledge. Contrasting to sociological and psychological theories where the individual is the central, basic unit of society (Smith L.T., 1999), Indigenous concepts of self and well-being are relational, spiritual and cyclical. The foundation of theoretical models in Indigenous research, particularly with respect to mental health and well-being, must therefore support a holistic perspective.

11 Methodology

The Indigenous research paradigm is currently undergoing a phase of rebuilding. Consequently, there is a tremendous need to develop the tools, knowledge and systems that support and facilitate community driven approaches to research. Theory and complementary methodologies are required at each stage of this process. I have chosen to focus on two methodologies that build on the theoretical perspectives described in the previous section and that uphold Indigenous values.

11.1 Mixed Methods

11.1.1 Background

Mixed methods research is a growing discourse that brings together ideas from both qualitative and quantitative inquiry within the social sciences and has received increased

attention and recognition over the past several years. A strong connection can be observed between mixed methods and the concept of triangulation, defined by Denzin as the combination of methodologies in the study of the same phenomenon resulting in the three possible outcomes of convergence, inconsistency and contradiction (Denzin N.K., 1978). Researchers in the social sciences, employ triangulation of data and methods for the purpose of confirmation, to bolster the reliability or validity of their findings, in order to obtain completeness or complementary perspectives and to make retroductive inferences about the mechanisms underlying their research strategy (Risjord M., Maloney M., & Dunbar S., 2001). In addition to triangulation, support for mixed methods research has also been framed as a means of expanding the breadth and range of inquiry, as an iterative process of allowing results generated from one method to inform and clarify another method, and as a way to enrich the meaning or depth of research findings (Greene J.C., Caracelli V.J., & Graham W.F., 1998; Rossman G.B. & Wilson B.L., 1985). More recently, Collins et al. identified four grounds for engaging in mixed methods research: ensuring appropriate inclusion of participants through optimal sampling techniques, assessing feasibility and appropriateness of existing or new instruments, measuring the integrity of a particular intervention and facilitating thickness of data and usefulness of findings (Collins K.M.T., Onwuegbuzie A.J., & Sutton I.L., 2006). Such justifications and arguments for mixed methods have emerged in a variety of research settings and disciplines ranging from nursing and health care to policy analysis. Moreover, in the first volume of the Journal of Mixed Methods Research, Johnson et al. proposed that mixed methods research should stand on its own as a distinct, third, research paradigm (Johnson R.B., Onwuegbuzie A.J., & Turner L.A., 2007). Not surprisingly, in response to these claims, a corresponding debate and intellectual analysis of the merits and failings of mixed methods has also surfaced. Much of the debate about the conceptualization of mixed methods stems from an existing tension between the two very distinct epistemological foundations of qualitative and quantitative inquiry.

11.1.2   Conceptualization

One of the greatest challenges facing researchers engaging in mixed methods is establishing an appropriate and consistent framework from which to position themselves. Firstly, one must consider the two very distinct meanings of 'methods' and 'methodology' and how these interpretations are applied to 'mixed methods research'. Denzin and Lincoln clearly distinguish the two by referring to methodology as the theoretical assumptions and principles

that stem from different disciplines and which guide our research versus methods, which are the tools we utilize to collect and analyze data, what we employ to generate outcomes (Denzin N.K. & Lincoln Y.(eds), 2005). In the context of mixed methods, however, this distinction appears blurry, as there are inconsistencies with respect to what is actually being mixed. Johnson et al., argue for a broad definition of methods, such that mixed methods allow for the inclusion of different methods of data collection (e.g. questionnaires, interviews, observation), different methods of research (e.g., ethnography, experimental design) and different philosophical approaches (e.g. epistemology, axiology) (Johnson R.B. et al., 2007). Creswell, on the other hand, proposes a narrower conceptualization of mixed methods, where mixing of methods is limited to processes of data collection, analysis and presentation (Creswell J.W., 2003). I lean more towards the broader conceptualization of mixed methods described by Johnson et al. If 'mixing' can occur at several stages of the research process, this allows for various voices and experiences to be heard, making it an approach that is more inclusive and therefore, consistent with Indigenous-centric methodologies.

Despite the many different conceptions and approaches to mixed methods, there have been attempts by leaders in the field to characterize this discourse. In the first issue of the Journal of Mixed Methods, Johnson et al., compiled, coded and extracted themes from 19 different definitions provided by various mixed methods research methodologists in the field and came up with the following definition based on their analysis:

> Mixed methods research is the type of research in which a researcher or team of researchers combines elements of qualitative and quantitative research approaches (e.g., use of qualitative and quantitative viewpoints, data collection, analysis, inference techniques) for the broad purposes of breadth and depth of understanding and corroboration. A mixed methods study would involve mixing within a single study; a mixed method program would involve mixing within a program of research and the mixing might occur across a closely related set of studies (Johnson R.B. et al., 2007).

While this may serve as an appropriate starting point or as a general guideline representing some of the shared concepts that are currently expressed by researchers in the field, I am not convinced of the utility or instructiveness of such a definition. Furthermore, the generality of these statements leaves the door wide open for interpretation, which in turn has implications for

research practice and outcomes. In any research endeavor, we must not assume that our approach, objectives or practices are transparent and that we come from a common understanding, even within the same discipline. Mixed methods research is a growing field and one that lends itself to a diversity of interpretations and applications; therefore it is imperative that we ascribe to consistent and clearly articulated positions and arguments throughout each stage of the research process. Transparency is of crucial importance in Indigenous research given the imbalanced, non-inclusive and unjust relationship that has characterized most Indigenous research endevours both historically and today.

11.1.3 Application

Bringing together elements from qualitative and quantitative research domains is the underlying principle of mixed methods research, however, there is not one recipe outlining the optimal manner and degree to which these components should be integrated. It has been suggested that the criteria for making these decisions rests on three considerations: an appropriate match between the research question and the approach used, the personal experiences, training and familiarity of the researchers with different approaches and the audience to whom the research will be reported and presented (Creswell J.W., 2003). The obvious criticism with these recommendations is the complete absence of the voice of those who are being targeted by such research. The pursuit of mixed methods must also align with community priorities and needs.

This argument is summarized nicely by Lynne Giddings who argues for collaborative inquiry and the blending of approaches among people who share a common motivation to affect change on a particular issue affecting their lives. She states:

> I suggest that the 'mixing' approach which works most effectively for local and Global well-being and social action is multi-methodological co-operative inquiry. People with a variety of backgrounds, some with research skills, but all with a shared concern and interest, design and carry out a multi-methodological study that has relevance to the needs of their diverse community. No matter what the paradigmatic positioning, if a co-operative inquiry framework is used, there is a chance we can move beyond methodological competitiveness to collectively dealing with social and health disparities and issues (Giddings L.S., 2007).

Mixed methods research affords a flexibility and inclusiveness that make it a fitting approach in the context of community-based research. In recent requests for proposals, the Canadian Institute for Health Research- Institute of Aboriginal Peoples' Health (CIHR-IAPH) has explicitly encouraged the integration of qualitative and quantitative methods to investigate factors leading to improved health of urban aborignal people and communities. More specifically, in the context of Aboriginal mental health, there is a lack of culturally appropriate tools and methods for identifying and measuring these issues as well as large gaps in our understanding of of suffering and healing experiences among this population. Mixed methods research would afford a multi-disciplinary, integrated approach to exploring these issues and generating knowledge.

11.2 Community-Based Research Methods

Traditionally, epidemiological narratives have portrayed the Aboriginal community as being sick and miserable which contributes to the overall public's understanding and the social construction of Aboriginal identity (O'Neil J.D., Reading J.R., & Leader A., 1998). Such portraits generate an image of communities that are ill and disorganized and can reinforce dependency and the power of paternalism (ibid). Research institutions and communities themselves are resisting this type of narrative and developing tools, guidelines and principles for more ethical, inclusive and community-based research (CBR) on health issues. Canadian cultural anthropologist Christopher Fletcher explains, "As a philosophy, CBR is inclusive of different ways of seeing the world. It incorporates multiple perspectives. It recognizes local knowledge systems as valid on their own epistemological foundations and views them as contributing to a larger understanding of the world and the place of humans in it. It takes as an a priori assumption that research and science are not value free. They can be used to help people help themselves in their daily struggles or they can be used to subjugate local opinion and action" (Fletcher C., 2003).

Various stakeholders in academic, political and community arenas have identified community-based research (CBR) as an appropriate approach to Indigenous research, specifically in the area of mental health and healing. In response to the RCAP, the Canadian government produced a report in 1998 entitled, *Gathering strength: Canada's Aboriginal action plan,* which was intended to initiate a process of reconciliation and renewal. A key outcome of this report was the establishment of the Aboriginal Healing Fund (AHF), a federally funded,

Aboriginally run, non-profit organization to support community-based healing projects aimed at addressing the abuses and trauma resulting from residential schools (Minister of Indian Affairs and Northern Development, 2000). More recently, the Canadian Institute for Health Research Guidelines for Health Research Involving Aboriginal peoples highlighted the importance of a more community-based approach to research. Specifically, Article 3 states:

> Communities should be given the option of a participatory-research approach. Genuine research collaboration is developed between researchers and Aboriginal communities when it promotes partnership within a framework of mutual trust and cooperation. Participatory research enables a range of levels and types of community participation while ensuring shared power and decision-making. Such partnerships will help to ensure that research proceeds in a manner that is culturally sensitive, relevant, respectful, responsive, equitable and reciprocal, with regard to the understandings and benefits shared between the research partner(s) and Aboriginal community(ies) (Canadian Institute for Health Research (CIHR), 20097).

It is in the context of community-based research (CBR), that I envision the appropriate application of mixed methods. In her review of community-based research and partnerships, Barbara Israel makes the recommendation that methodological flexibility is crucial in CBR in order to ensure that the methods used are not only tailored to meet the research objectives, but are also reflective of the community needs and interests (Israel B.A., Schulz A.J., Parker E.A., & Becker A.B., 1998). Furthermore, Israel found that many researchers in this field suggested an increased application of qualitative assessment and data to evaluate CBR processes and outcomes (ibid). In CBR, there are multiple levels of action and engagement occurring simultaneously. On the one hand, the research aim of the project or intervention may be tailored to answer or understand a particular phenomenon, while on the other hand, participation and involvement in the research process builds capacity and encourages social action at the community level. Therefore, embedded in CBR processes are different ways of constructing knowledge and different layers of reality. Mixed methods models, therefore, may be an effective and acceptable approach to gaining access to these distinct and complex levels of engagement, practice and outcomes.

CBR has been interpreted and administered in diverse contexts and has generated a broad range of results, both positive and negative. This multiplicity of applications has led to inconsistency and liberal understandings of what it means for research to be community-driven (Smylie J. et al., 2011b). There are different interpretations about the various stages and processes of CBR, the role of different stakeholders and the many levels of involvement. As Smith explains, "Defining community research is as complex as defining community…What community research relies up and validates is that the community itself makes its own definitions" (Smith L.T., 1999).

In her review of CBR programs, Israel identified several strategies on how to address some of the methodological challenges in CBR that included: involving community members in the development of measurement tools, data collection and interpretation of findings, establishing community-research partnerships and agreements, and creating interdisciplinary research teams who integrate their experiences in innovative ways (Israel B.A. et al., 1998). More specific to Aboriginal communities is Fletcher's framework for CBR that includes: addressing the imbalance of power between Aboriginal communities; the state and its institutions; universities and researchers, accepting the diversity of ways of seeing and understanding the world as positive, developing capacities within the community that contribute towards self-sufficiency and self-determination, approaching research as an opportunity to provide public education about research in general and the issue at hand and respect the ethical guidelines established by organizations that represent the interests of Aboriginal peoples (Fletcher C., 2003).

11.2.1   Community-Based Research and Self-Determination

Self-determination has been used in the context of self-governance and empowerment in the Indigenous research literature. The goal of self determination however, is more than a political effort, but one of social justice that involves processes of transformation, decolonization, healing and mobilizing (Smith L.T., 1999). According to Smith, "To imagine self-determination is also to imagine a world in which Indigenous people become active participants and prepare for the possibilities and challenges ahead" (Smith L.T., 1999).

Rigney supports this notion that Indigenous people are at a stage where they want research and research design to contribute to their self-determination and liberation struggles, as it is defined and controlled by their communities (Rigney, 1999). Research developed in this

way would result in an enrichment of people's lives as opposed to feelings of oppression or depletion (Weber-Pillwax C., 1999). For Rigney, 'Indigenist' research is a form of protest and liberation that cannot be isolated from the Australian political context and must embrace the lived experiences and history of Indigenous peoples (Rigney, 1999).

According to the United Nations report on the State of the World's Indigenous People, self-determination is considered a pre-condition for exercising one's human rights and more specifically, the restitution of Indigenous self-determination has been identified as a key pathway for the improvement of Indigenous health (United Nations Department of Economic and Social Affairs, 2009; International Symposium on the Social Determinants of Indigenous Health, 2007). The National Aboriginal Health Organization cites self-determination as one of the key challenges facing Aboriginal peoples and proposes that, "Research is required to further explore the relationship between Aboriginal social, political and economic self-determination and health, effective ways to foster better understanding of the inherent right to and value of self-government for Aboriginal Peoples, and ways to remove barriers to personal empowerment, and effective leadership and participation in decision making" (National Aboriginal Health Organization (NAHO), 2003).

For Aboriginal people in Canada, there is growing recognition of data ownership and community control over all research processes. Originating from discussions held by the National Steering Committee of the First Nations Regional Longitudinal Health Survey (RHS), Ownership, Control, Access and Possession (OCAP) is broadly concerned with all aspects of information, including its creation and management (Schnarch B., First Nations Centre, & National Aboriginal Health Organization, 2004). OCAP emerged in response to dominant, colonial research methods and control of information and it, "opens up new avenues for the expression of self-determination and self-governance in the areas of research and information and provides a measure of hope for positive change" (ibid). Thus a very important social implication of OCAP is that negative views of Aboriginal people in Canada will be undone and strength and resiliency will be revealed (Elias B., O'Neil J.D., & Sanderson D., 2004).

Many Aboriginal communities have moved beyond OCAP and have developed their own models for control and ownership of research.   For example, the Métis Centre of the National Aboriginal Health Organization (NAHO) has established its own Principles of Ethical Métis

Research as a Métis-specific tool for those engaging Métis communities in research (Métis Centre-National Aboriginal Health Organization, 2010). Similarly, the Inuit Tapiriit Kanatami, the national Inuit organization in Canada has developed Inuit-specific policies around negotiating research relationships, conducting research and knowledge governance (Inuit Tapiriit Kanatami & Nunavut Research Institute, 2007). While OCAP and other research ownership processes have begun to be applied in research settings, its role in public health programming and evaluation has not been fully explored (Tait C.L., 2008). Initiatives that are rooted in Aboriginal knowledge systems and developed and controlled by Aboriginal people themselves are emerging, but slowly, given that the majority of public health funding supports Western methods and models of prevention and treatment, especially in urban settings (ibid, p31). CBR is one approach whose foundation and rationale create the necessary space for Aboriginal initiative and ultimately, self-governance.

Chapter 4
Our Health Counts: An Overview of Research Development, Setting and Data Collection

In this chapter, I will provide the broader context of the Our Health Counts (OHC) project in order to situate the three papers of this thesis.

12 Preliminary Project Development

In 2007, discussions around the need for a research project to address the gaps in population based data for urban Aboriginal populations in Ontario began between the executive director of the Ontario Federation of Indian Friendship Centres (OFIFC) and the project research lead at St Michael's Hospital. Building on existing research relationships, Tungasuvvingat Inuit (TI), the Métis Nation of Ontario (MNO) and the Ontario Native Women's Association (ONWA) joined the project team over the next several months. A small grant from the Public Health Agency of Canada was used to fund a research planning meeting in March 2008. At this meeting, research principles, partnerships, and methods were further developed. A full research proposal was submitted by OFIFC on of behalf of the research partners to the Aboriginal Health Transition Fund of the Ministry of Health and Long Term Care (MOHLTC) of Ontario in June 2008. The project was formally initiated in January 2009 as an 18-month adaptation pilot project funded by the MOHLTC.

13 Project Objectives

The goal of the Our Health Counts (OHC) project was to work in partnership with Aboriginal organizational stakeholders to develop a baseline population health database for urban Aboriginal people living in Ontario that is immediately accessible, useful, and culturally relevant to local, small region, and provincial policy makers.

The eight OHC project objectives were established around four main areas:

Formalizing Intersectoral Partnerships and Establishing Priority Measures

1. To formalize partnerships between the four core urban Aboriginal provincial organizations, the multidisciplinary academic team, the Ontario MOHLTC, and the Institute for Clinical

Evaluative Sciences (ICES) for this project through research agreements and data management/governance protocols. This included the establishment of an Aboriginal Health Data Governance Council comprised of the four core urban Aboriginal provincial organizations.

2. To confirm priority health domains and best indicators for each domain through these partnerships.

Knowledge Development through Establishment of a Population Health Data Base

3. To generate new health data sets reflective of these priorities for a sample of urban First Nations, Inuit, and Métis adults and children using respondent driven sampling, secure data linkage with ICES and a rapid health assessment questionnaire.

Capacity Building, Training and Mentoring

4. To strengthen capacity and leadership among Ontario's urban Aboriginal communities and their policy, program and health service collaborators in the area of Aboriginal health information collection, analysis, and application through: a. the involvement of community representatives as active research team members in all aspects of this project; b: a series of community-based health data use workshops.

5. To provide a scientifically excellent and culturally relevant training and mentorship environment for Aboriginal health researchers at the undergraduate, graduate, post-doctoral and new investigator level.

Knowledge Dissemination, Application, and Contribution to Future Projects

6. To support community-based, small region, provincial, and federal uptake and application of health data generated through 1-3 above to First Nations, Inuit, and Métis health policies, programs, and services.

7. To build on the outcomes of this study to design future longitudinal health studies in partnership with First Nations, Inuit, and Métis governing/organizational stakeholders as well as additional strategies to improve the quality of First Nations, Inuit, and Métis health data in Ontario.

8. To share study results and adaptation processes with First Nations, Inuit, and Métis stakeholders in other provinces and territories and thereby contribute to the development of urban Aboriginal health data enhancement strategies.

14   Project Governance

The core organizations involved in the Our Health Counts Project agreed upon the following research principles:

- Aboriginal Leadership

- Research Agreements and Data Management/Governance Protocols

- Capacity Building

- Respect

- Cultural Relevance

- Representation

- Sustainability

The first principle, Aboriginal project leadership, was operationalized by the establishment of the Our Health Counts project Governing Council, which was comprised of representatives from OFIFC, MNO, TI, and ONWA as voting members and Dr. Janet Smylie from CRICH as a non-voting governing council participant who was also identified as the scientific director for the project. Monthly Governing Council meetings were held throughout the length of the project.

The second principle, research agreements and data management and governance protocols, was operationalized in a way that ensured that the OHC Governing Council as well as the First Nations, Inuit, and Métis community project partners were able to exercise their rights to govern and manage project data, including the rights to own, control, have access to and possess project data. To start with, the four Governing Council organizational members developed and signed a project MOU. Next, the OHC project team successfully developed and negotiated community research agreements with each of the three community project sites (Appendices A, B and C).

Finally, a tri-party data sharing agreement was negotiated between the Institute of Clinical and Evaluative Service, the OHC Governing Council and CRICH at St Michael's hospital (Appendix D). The OHC project was approved by the Research Ethics Board of St. Michael's Hospital in Toronto

15   Study Sites

The OHC project was implemented in three communities and with three urban Aboriginal populations: First Nations in Hamilton, Inuit in Ottawa, and Métis in Ottawa. The community partners representing these populations were De dwa da dehs ney>s Aboriginal Health Access Centre (on behalf of the Hamilton Executive Directors Aboriginal Coalition) in Hamilton, Métis Nation of Ontario (MNO) in Ottawa and Tungasuvvingat Inuit Family Health Team (TIFHT) in Ottawa.

Hamilton was chosen as the First Nations project community site because of its significant Aboriginal population (13,735 persons reporting Aboriginal ancestry according to the 2006 Census) and strong infrastructure of Aboriginal community health and social services (Statistics Canada, 2007b). The MNO identified the City of Ottawa as a promising Métis community project site for the OHC project. This decision was based on the sizeable local Métis population identified in the 2006 Census (Statistics Canada, 2008) and the accessibility to local supports from the Nation of Ontario provincial office, which is located in Ottawa. Tungasuvvingat Inuit provides health and social services to the Inuit population in Ottawa and was therefore an appropriate Inuit study site. Furthermore, the largest population of Inuit living outside of Nunaat is in Ottawa (Statistics Canada, 2008), a number that represents a significant underestimate according to TI who serve an Inuit population in Ottawa several times larger than the census population estimate.

16   Research Methods Overview

- This project was carried out using community based research (CBR) methods.

- The CBR approach promoted balance in the relationships between the Aboriginal organizational partners, academic research team members, Aboriginal community

participants and collaborating Aboriginal and non-Aboriginal organizations throughout the health information adaptation process, from initiation to dissemination.

- This was achieved through the project governing structure including the project Governing Council and research and data sharing agreements described above as well as ensuring that capacity building, respect, cultural relevance, representation, and sustainability were core features of the project's ongoing overall and day to day implementation.

- Using Concept Mapping, brainstorming, sorting and rating of health priorities and concerns among key health and social service stakeholders serving First Nations, Inuit and Métis communities in Hamilton and Ottawa generated three unique maps (Paper #1)

- The three concept maps informed the development of three unique survey tools for First Nations in Hamilton, Métis in Ottawa and Inuit in Ottawa.

- A respondent driven sampling (RDS) technique was used to recruit individuals to be interviewed for the research. This method involved giving coupons to each First Nation, Métis or Inuit participant who completed an interview, and these individuals could then give these coupons to other First Nations, Métis or Inuit people they knew, including friends and family. For each participant recruited, the person who made the recruit received $10. (First Nations results, Paper #2)

- When Study participants gave permission, Ontario Health Insurance Plan (OHIP) numbers were collected and linked to health care system usage data available through the Institute for Clinical Evaluative Sciences (ICES) (First Nations income quartile linkage data, Paper #2)

- Data analysis was conducted using a RDS-specific software called RDSAT (volume 6). For each community, population estimates were generated for health and social characteristics of interest (Sociodemographic, mental health and substance misuse variables are presented in Paper #2 and Paper #3)

Chapter 5 Paper #1: Concept Mapping: Application of a Community-Based Methodology in three Urban Aboriginal Populations

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Abstract

Background: The goal of the Our Health Counts project was to develop accessible and culturally relevant urban Aboriginal health information in Ontario. Concept mapping was used to engage urban Aboriginal community stakeholders in identifying community health concerns and priorities. The following three communities were involved: First Nations people in Hamilton through De dwa da dehs ney>s Aboriginal Health Access Centre (DAHC), Inuit people in Ottawa through Tungasuvvingat Inuit Family Health Team (TIFHT) and Métis people in Ottawa through the Métis Nation of Ontario (MNO).

Methods: Up to 40 key stakeholders from each community participated in the three concept mapping activities: (1) Group Brainstorming, (2) Group and Online Sorting and Rating and (3) Group Map Interpretation. Participants generated statements regarding health and health related issues in their communities that were relevant, serious, had the fewest solutions, or were otherwise important. Statements were sorted into piles that made sense to each participant and were rated according to service availability, need for health information and overall health concern. Concept systems software uses non-metric multidimensional scaling and cluster analysis to create point and cluster maps reflecting the overall group sort and rate.

Results: The number of final statements varied in each community, ranging from 44 to 102. When developing their unique maps, participants in each community opted for the number of clusters that best suited their understanding of health. Each cluster represented a community health domain. The chosen labels for these domains and their ratings strongly reflected local First Nations, Inuit, and Métis understandings of health.

Conclusions: Concept mapping is an effective and culturally relevant community based method for urban Aboriginal health research as it builds on traditional Indigenous methods, encourages cross-community participation and can contribute to health assessment survey tools that reflect local understandings and Indigenous-specific social determinants of health.

Introduction

There are striking health and social inequities between Aboriginal and non-Aboriginal people in Canada. For First Nations, Inuit, and Métis people, ill health is directly linked to social determinants of health including colonization, cultural suppression, family and community dislocation, chronic unemployment, poverty, lower education attainment, and unhealthy environments (National Aboriginal Health Organization (NAHO), 2003; International Symposium on the Social Determinants of Indigenous Health, 2007). In the face of these challenges, it is very important to recognize that many Aboriginal individuals and communities still have experiences of good health and well-being, demonstrating resilience, celebrating cultural values and actively transmitting cultural knowledge and traditions to younger generations (Kirmayer L.J. et al., 2009). Research in this context must therefore adhere to a framework that upholds the local diversity of knowledge systems and resiliencies among Indigenous communities and also recognizes the continued negative health impact of colonization on this population. (Smylie J. et al., 2009). Furthermore, there is a tremendous need to develop the tools, knowledge and systems that support and facilitate community driven approaches to research.

According to the 2006 Census, over 60% of Aboriginal people in Ontario live in urban areas. In Canada, nearly seven out of ten Métis live in urban areas and about three out of every four people in the off-reserve First Nations population live in urban areas (Statistics Canada, 2008). In other words, the most urbanized groups are non-status Indians and Métis with 73% and 69%, respectively living in urban areas (Norris M.J. et al., 2003). Urbanization is also increasing among Inuit people with the largest urban population residing in the city of Ottawa (Gionet L., 2008). The majority of Aboriginal individuals and communities have experienced historic dislocation from their original homelands.

In urban areas Aboriginal communities may be diasporic and heterogeneous (Canadian Institute for Health Research (CIHR), 20097). Specifically, an increasing number of First Nations are moving to urban centres to seek better housing, employment and health care (National Aboriginal Health Organization (NAHO), 2003). We know from the Canadian Census that First Nations, Inuit, and Métis populations experience ongoing disparities in social determinants of health such as income insecurity, unemployment, low levels of education,

decreased food availability, and inadequate housing compared to non-Aboriginal Canadians and that these disparities are exacerbated with urban residence (Statistics Canada, 2008).

Population health outcomes data on First Nations, Métis and Inuit populations living in urban areas are very limited. Some of the reasons behind this deficiency are due to limitations in the current health information system and data collection processes with respect to Aboriginal peoples (Smylie J. et al., 2010; Smylie J. et al., 2011b; Smylie J. et al., 2006b). In addition to gaps in the coverage of existing data systems, there is an enormous disconnect between the large majority of data systems and the Aboriginal communities whose data are being collected. So, in addition to poor quality data, the health indicators themselves are mostly developed externally to Aboriginal communities as there is little infrastructure or resources to support Aboriginal-specific data processes (Anderson M. & Smylie J., 2009). Moreover, a history of negative experiences in Canada and in other Indigenous contexts worldwide has led to mistrust between Indigenous communities and researchers and government bodies, creating a barrier that perpetuates the broader social exclusion of Indigenous populations (Anderson M. et al., 2006; Smylie J. et al., 2011b). There is a tremendous need to develop the tools, knowledge and systems that support and facilitate community driven approaches to research, rather than those that reinforce marginalization and exclusion.

In Canada and internationally, Indigenous people want research and research design to contribute to culturally relevant health measurement systems that are not pan-Indigenous, but that incorporate traditional healing frameworks and focus on community wellness (Anderson M. et al., 2009; Kirmayer L.J. et al., 2009). Research developed in this way would result in an enrichment of people's lives as opposed to feelings of oppression or depletion (Weber-Pillwax C., 1999). Concept mapping was selected as a research tool that supports local knowledge and establishes a conceptual foundation upon which data measurements and systems can be grounded.

Mapping of Indigenous knowledge around a topic or concern of interest through concept mapping is a culturally relevant and appropriate community-based participatory method for urban Aboriginal research. It is also not a new concept. One form of mapping that has been used in Canadian Aboriginal communities is traditional land-use mapping. Land-use maps illustrate the knowledge and experiences that Indigenous people associate with specific geographic areas

and or landmarks and demonstrate how one aspect of the Indigenous knowledge held by community members can be mapped in a manner that has meaning for that community. The mapping process can build community capacity and may have the potential to affect environmental and social policy decisions (Robinson M., Garvin T., & Hodgson G., 1994; Kassam K.A. & Graham J.R., 1999).

Concept mapping is a very inclusive process that requires input from participants at each stage (Burke J.G. et al., 2005). There are several advantages to using concept mapping: it encourages participant groups to stay on task and to lay out relatively quickly a framework for a planning or evaluation study, it uses the language of the participants rather than terms imposed by an evaluator or planner, it appears to increase group cohesiveness and morale, it generates a graphic representation which at a glance shows all of the major ideas and interrelationships, the map is comprehensible to all of the participants and can be presented to other audiences easily (Trochim W.M.K., 1989). It was anticipated that concept mapping would be an appropriate tool in urban First Nations, Inuit and Métis research contexts as it builds on mapping traditions, it upholds collective values and opinions and it requires strong community participation. While, there is little documentation of concept mapping in an urban Aboriginal research setting, it has been successfully implemented with marginalized groups in urban, community based research contexts (Burke J.G., O'Campo P., & Peak G.L., 2006; Burke J.G., O'Campo P., Salmon C., & Walker R., 2009; O'Campo P., Salmon C., & Burke J.G., 2009).

In the Our Health Counts project, concept mapping was selected as a tool for engaging stakeholders in a health needs assessment and database development project carried out in partnership with three distinct urban Aboriginal populations in Ontario. In each of the three communities, the resultant cluster maps were used to directly inform the development of a unique survey tool. This project was funded by the Ministry of Health and Long Term Care (MOHLTC) Aboriginal Health Transition Fund, the Ontario Federation of Indian Friendship Centres (OFIFC) and the Centre for Research on Inner City Health (CRICH) at St. Michael's Hospital. The organizational partners include OFIFC, Métis Nation of Ontario (MNO), Ontario Native Women's Association (ONWA), Tungasuvvingat Inuit Family Health Team (TIFHT) and the Centre for Inner City Health Research (CRICH), Saint Michael's Hospital. There were three project community sites: First Nations in Hamilton, Inuit in Ottawa, and Métis in Ottawa. The community partners representing these populations in Hamilton and Ottawa were De dwa da

dehs ney>s Aboriginal Health Access Centre (on behalf of the Hamilton Executive Directors Aboriginal Coalition), MNO and TIFHT. Concept mapping activities were conducted between June and November of 2009.

Methods

Recruitment

Concept mapping was used to engage urban Aboriginal community stakeholders in the three project sites. The city of Hamilton was selected as a promising First Nations community project site, based on its significant Aboriginal population and strong infrastructure of Aboriginal community health and social services. Ottawa was chosen as the Inuit site as it has the largest urban Inuit population in Canada (Statistics Canada, 2008) and the principle investigator had a working relationship with the community for more than 10 years. Similarly, Ottawa was chosen as the Métis site to build on an existing research relationship and due to the fact that the Métis Nation of Ontario provincial office is located in Ottawa and was able to provide support for the project. Finally, both Hamilton and Ottawa were chosen based on their proximity to the research team, which facilitated regular meetings and supported a participatory action research framework (Smylie J. et al., 2011a; Smylie J. et al., 2012).

A separate concept mapping project was completed for each of the three community sites in recognition of the diverse historical, cultural, political, and social contexts of the three partner communities. This was also in keeping with current policy regarding the need for contextually specific First Nations, Inuit, and Métis research and services in Canada (Smylie J. et al., 2006b; Smylie J. & Anderson M., 2006) as well as existing literature that describes unique and specific understandings of health across First Nations, Inuit, and Métis communities (Renfrey G. & Dionne R., 2001; Bartlett J., 2007).

Front line health and social service workers from Aboriginal organizations serving these communities were invited to participate in the concept mapping process. Participant recruitment was led by each of the community site research coordinators and supported by the larger research team. The selection of participants was achieved through purposive sampling in order to ensure group diversity with respect to organizations represented, gender, age, occupation, and community roles (i.e. both Aboriginal organizational staff and clients were included). Therefore,

community members were identified on the basis of addressing the research goal to access across sectors of each community and not with the intention to ensure generalizability (Burke J.G. et al., 2009; Smylie J. et al., 2009). The research coordinators in each of the three community sites invited participants either in person, by phone or email. In Hamilton, these individuals represented member organizations of the Hamilton Executive Director's Aboriginal Coalition (HEDAC) as well as other sectors of the community (students, parents, industrial workers, and health and social service clients). In Ottawa, Métis participants were staff, clients and/or members of the Métis Nation of Ontario, the National Aboriginal Health Organization, the Métis National Council and the Ottawa Métis Council. Inuit participants included front line workers and clients from Tungasuvvingat Inuit Family Health Team as well as artists, elders, and other prominent Inuit community members.

Concept mapping activities

Concept mapping integrates several qualitative and quantitative methods into a series of structured steps. Each participant must complete three data gathering activities: brainstorming, sorting and rating and map interpretation or diagramming. All data collection activities were approved by St. Michael's Hospital Research Ethics Board and the Governing Council comprised of the four core urban Aboriginal provincial organizations involved in the project.

Brainstorming

In the three community sites, brainstorming activities were conducted in a group session on site at the participating community organizations. On average, the brainstorming sessions lasted approximately 2 hours long. All three groups responded to the following focal question:

"Health and health related issues and topics in the Hamilton First Nations/Ottawa Métis /Ottawa Inuit community that are prevalent, serious, have the fewest solutions, or otherwise important include......"

Following concept mapping guidelines, the list of non-unique items generated in each brainstorming session were combined into one master list of items by combining repetitive statements, statements that did not answer the focal question, and removing duplicates (Kane M. & Trochim W.M.K., 2006). In Hamilton, there were two group sessions with a total of 16

participants and a master list of 102 statements. For Inuit in Ottawa, there was one brainstorming session with 24 participants and a total of 44 statements were generated. Finally, for Métis in Ottawa, there was one group session, 11 participants and 83 statements generated (Master Lists of Brainstorming Statements: Appendix E).

Sorting and rating

For the First Nations in Hamilton and the Métis in Ottawa, the sorting and rating sessions were conducted online using internet software provided through the Systems Concepts Global package. Participants were sent an email that contained their password and log-in information in order to access the list of statements that were generated at the brainstorming sessions. Participants were told that the process would take around 3 hours to complete and that it would be possible to save their work and complete it in several sittings. Additionally, arrangements were made with the participating community agencies and organizations so that individuals could take time during the work day to complete the sorting and rating activities. Finally, a support/help line during regular working hours was provided to the participant to answer any questions that may have arisen. In Hamilton, 15 individuals completed the online sorting and rating and for the Métis in Ottawa, 20 individuals completed both online activities. The online sorting and rating took two weeks to complete.

Due to the need for a bilingual session in English and Inuktitut, the sorting and rating for the Inuit in Ottawa occurred in person at the TIFHT community centre. The total number of participants was 20. The group session lasted approximately 4 hours.

For the sorting task, both online and in person, participants were asked to place the items from their particular master list into piles that made sense to them and label the piles accordingly. All participants were provided with the following instructions: each individual statement can only be placed in one pile, all statements can't be placed in the same pile and all statements can't be placed into their own pile. After completing the sorting, participants were asked to rate the statements with respect to the following three areas:

1. Community Concern:

When you consider each of the statements, please rate them according to your degree of concern for the topic within your community. (Where 1= No Concern and 5= Extremely Concerned)

2. Health Data and Information:

When you consider each of statements, please rate them according to the need for health data and/or information to better understand the problem. (Where 1= No need for health data and 5= Extreme need for health data)

3. Service Availability:

When you consider each of the statements, please rate the extent to which services are available to address the particular issue. (For First Nations, Where 1=No services available and 5=Services are more than adequate and for Métis and Inuit, Where 1= Services are more than adequate and 5= No services are available)

Data from the online sorting and rating were automatically entered into the concept systems software (The Concept System (version 4.0)., 2005), while the data gathered during the group sorting and rating session were entered manually. Three core data analysis steps were conducted in order to develop the concept maps (Kane M. et al., 2006). First, each participant's sorting data were used to create a similarity matrix that contained information on the number of participants who sorted each pair of item statements together. The second step, multidimensional scaling, was used to position each statement on a point map. The third step involved hierarchical cluster analysis, which converted the point map into a cluster map by grouping similar items into non-overlapping clusters (Burke J.G. et al., 2005).

Map Interpretation sessions

In Hamilton, there were 2 map interpretation sessions with a total of 12 participants. In Ottawa, at the Inuit site, there was one map interpretation session with 20 participants and one map interpretation session for the Métis with a total of 9 participants. All map interpretation sessions were completed in a group setting on site at the participating community organizations.

Prior to the map interpretation sessions, the research group reviewed and adjusted the cluster maps generated by Concept Systems. By starting with a large number of clusters (i.e. 20),

at least 3 research team members reviewed the stepwise merging of clusters required for progressively smaller cluster solutions for each of the three maps. The optimal cluster solution was the one beyond which it did not make sense to merge clusters further because doing so would result in more than one unique conceptual domain per cluster (Kane M. et al., 2006). These initial cluster maps generated by the research team were projected onto a screen at the front of the room and in clear view of all participants in each map interpretation session. The statements contained in each cluster were closely examined and discussion was encouraged. Participants were able to explore the content of each cluster in great detail and were able to challenge the location of an item. The final cluster labels were also determined at these group sessions. A multidimensional scaling diagnostic statistic called a stress value was generated in order to confirm the appropriateness of the number of clusters to appear in the final map (Heckathorn et al., 1999; Burke J.G. et al., 2005).

Results

The results are presented here as three distinct concept mapping projects. Each community generated a separate map that was locally grounded and reflective of the diverse sociocultural, geographic and political contexts in urban First Nations, Inuit and Métis community sites. Also, the three community sites were comprised of different stakeholders who generated and sorted different statements, ensuing that separate analyses take place(Burke J.G. et al., 2006). For these reasons, all three maps are presented below.

First Nations, Hamilton

The master list of 102 statements were clustered around 10 domains that represent the health and health-related issues that are considered to be the most serious, important and with the fewest solutions for the First Nations community in Hamilton.

Figure 1. Hamilton First Nations Community Map
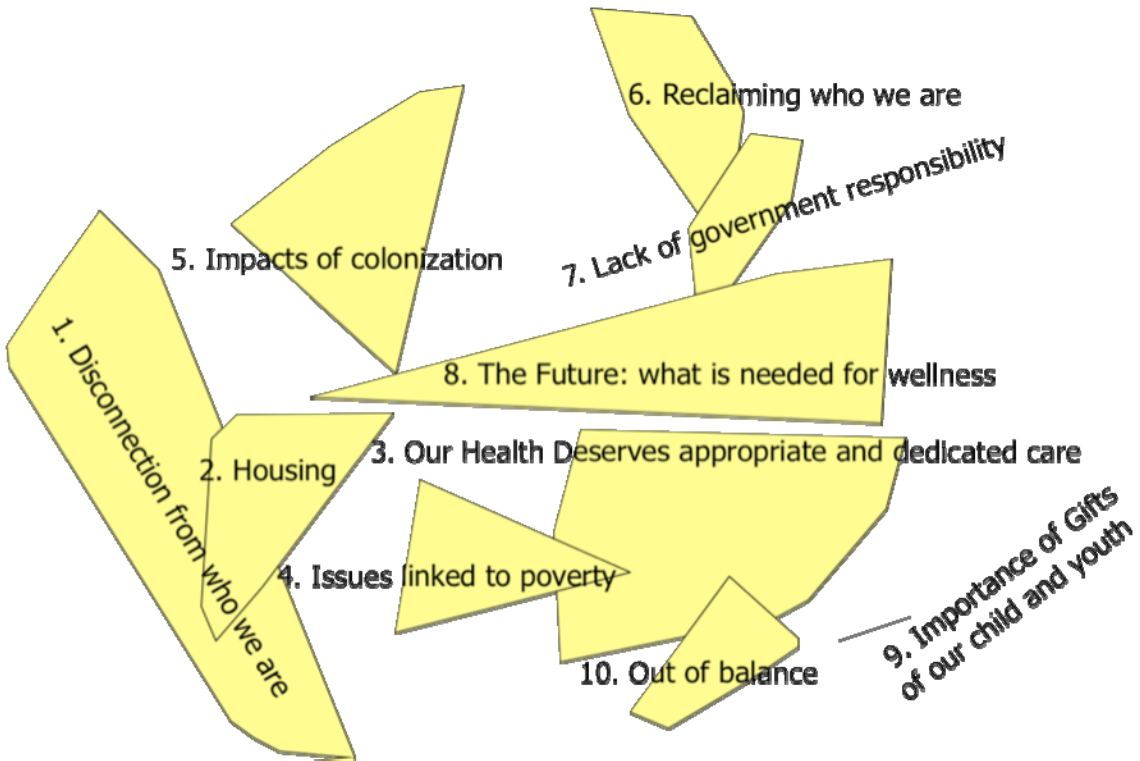
Inuit, Ottawa

The Inuit community in Ottawa produced a map with 7 domains representing the 44 statements.

Figure 2. Ottawa Inuit Community Map
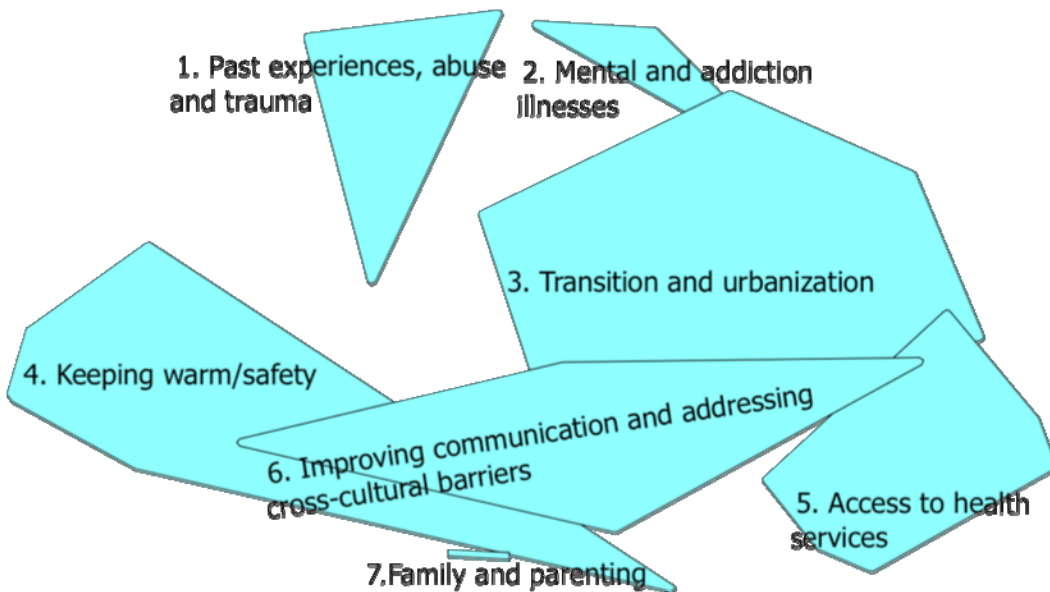
Métis, Ottawa

The Ottawa Métis community generated a 10-cluster map that represented the health and health-related concerns of their community.

Figure 3. Ottawa Métis Community Map
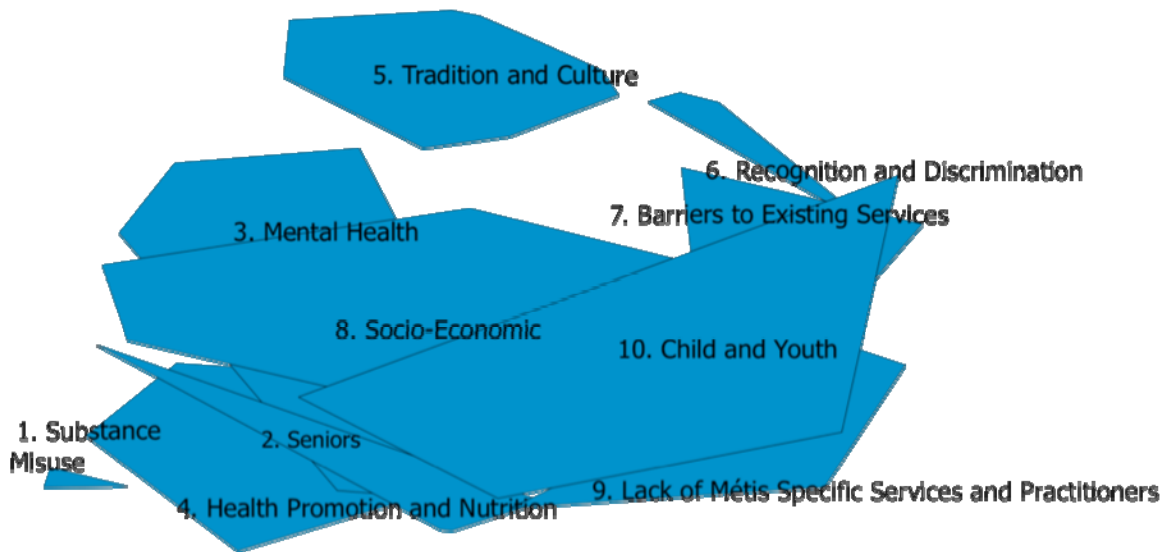
Clearly, the maps presented here depict three unique conceptualizations of health priorities in each of the three community settings. The configuration of the maps themselves, the cluster labels and the degree of concern or rating of each of the health topics are distinct. Of note, participants in all three mapping groups emphasized social and political determinants of health such as colonization, discrimination, trauma and lack of government responsibility as priorities for their communities, which is in stark contrast with the conceptual frameworks underlying more mainstream research instruments which focus more on individual-level, health status outcomes (i.e. Canadian Community Health Survey (CCHS)). A summary of the 5 top-rated map clusters for each of the three rating scales in the three community sites are presented below in tables 1-3.

Table 1. Top 5 Rated Clusters for Level of Community Concern in urban First Nations, Inuit and Métis Community Sites

Community	Cluster Label	Average Rating
Hamilton, First Nations	Issues linked to poverty	4.43
	Disconnection from who we are	4.36
	Impacts of colonization	4.34
	Housing	4.33
	Lack of government responsibility	4.28
Ottawa, Inuit	Mental and addiction illnesses	4.19
	Improving communication and addressing cross-cultural barriers	4.18
		4.18
	Keeping warm/safety	4.06
	Past experiences, abuse and trauma	3.84
	Access to health services	
Ottawa, Métis	Substance misuse	4.13
	Recognition and discrimination	4.03
	Socio-Economic	3.98
	Lack of Métis specific services and practitioners	3.90
	Health promotion and nutrition	
		3.85

Table 2. Top 5 Rated Clusters for Need for Health Data and Information in urban First Nations, Inuit and Métis Community Sites

Community	Cluster Label	Average Rating
Hamilton, First Nations	Impacts of colonization	4.46
	Issues linked to poverty	4.37
	The Future: what is needed for wellness	4.35
	Housing	4.32
	Our Health Deserves appropriate and dedicated care	4.30
	Lack of government responsibility	
		4.28
Ottawa, Inuit	Keeping warm/safety	4.22
	Improving communication and addressing cross-cultural barriers	4.16
	Past experiences, abuse and trauma	
		4.00
	Transition and urbanization	3.99
	Mental and addiction illnesses	3.96
Ottawa, Métis	Substance misuse	3.98
	Health promotion and nutrition	3.95
	Seniors	3.83

	Lack of Métis specific services and practitioners	3.81
	Socio-Economic	3.77
	Recognition and discrimination	3.74

Table 3. Top 5 Rated Clusters for Extent to Which Services are Available to Address this Issue in First Nations, Inuit and Métis Community Sites

Community	Cluster Label	Average Rating
Hamilton, First Nations	Issues linked to poverty	2.12*
	The Future: what is needed for wellness	2.15
	Out of balance	2.57
	Disconnection from who we are	2.64
	Importance of Gift of our child and youth	2.95
Ottawa, Inuit	Improving communication and addressing cross-cultural barriers	4.10
	Keeping warm/safety	3.90
	Transition and urbanization	3.81
	Access to health services	3.64
	Past experiences, abuse and trauma	3.53

Ottawa, Métis	Lack of Métis specific services and practitioners	3.93
	Recognition and discrimination	3.85
	Barriers to existing services	3.79
	Tradition and Culture	3.74
	Seniors	3.62

* The rating scale was reversed for First Nations, 1=No service available and 5=Services are more than adequate. Therefore, clusters with lower scores are those which the Hamilton First Nations felt had fewer services available to address these issues.

Overall, the average ratings for the top-5 clusters in each community indicate a high level of community concern, a great need for health data and information and a desire for more services in each setting.

Discussion

Our study has demonstrated that concept mapping can be a culturally relevant and appropriate community-based methodology for Indigenous contexts. Although concept mapping was developed drawing on Eurowestern research traditions, when applied appropriately in three diverse Aboriginal community settings, it supported the articulation and illustration of Indigenous conceptualizations of health. An illuminating example took place during one of the map interpretation sessions with the First Nations in Hamilton where community stakeholders identified and superimposed a medicine wheel on the concept map (Appendix G). The medicine wheel, made up of four quadrants is configured as a circle. It can function as a framework for understanding the interconnectedness and interrelatedness of the natural world, including the lived environment and all living things (Bopp M. et al., 2001; McCabe G., 2008). At the individual human level, the four quadrants can represent the holistic self (mind, body, emotions and spirit), while on a more collective level, one can superimpose stages of the lifecycle (child, youth, adult, senior/elder) or levels of social composition (individual, family, community, nations) (ibid). During this particular interpretation session, the medicine wheel and its four

quadrants were literally superimposed onto the concept map itself with two axes labeled: "Our Health Deserves Appropriate and Dedicated Care" and "Disconnection from Who We Are".

In addition to supporting the articulation of Indigenous ideas, concept mapping is grounded in community engagement and consensus, an approach that corresponds with the expressed desire across diverse Aboriginal communities to take a leadership position in research and health policy and practice (Smylie J. et al., 2011b; Rigney, 1999).   Likewise, concept mapping fits with the ethical standards in Indigenous research and can facilitate Indigenous self-determination and governance of health research processes and outputs, including Ownership, Control, Access and Possession (OCAP). Originating from discussions held by the National Steering Committee of the First Nations Regional Longitudinal Health Survey (RHS), Ownership, Control, Access and Possession (OCAP) is broadly concerned with all aspects of information, including its creation and management (Schnarch B. et al., 2004). OCAP emerged in response to dominant, colonial research methods and control of information (ibid). Many Aboriginal communities have moved beyond OCAP and have developed their own models for control and ownership of research.   For example, the Métis Centre of the National Aboriginal Health Organization (NAHO) has established its own Principles of Ethical Métis Research as a Métis-specific tool for those engaging Métis communities in research (Métis Centre-National Aboriginal Health Organization, 2010). Similarly, the Inuit Tapiriit Kanatami, the national Inuit organization in Canada has developed Inuit-specific policies around negotiating research relationships, conducting research and knowledge governance (Inuit Tapiriit Kanatami et al., 2007). Arguably, the procedures and results of concept mapping create the necessary space for Aboriginal initiative and ultimately, self-governance of knowledge processes and outputs. Rather than marginalizing Aboriginal knowledge and experiences, concept mapping supports the emergence of Aboriginal concepts through broad community participation.

Concept mapping is advantageous to Aboriginal communities as it efficiently generates a visual picture, which can contribute to the development of 'policy-ready' proposals that are easily grounded in a rigorous methodology and accessible to Aboriginal communities who are often under a lot of pressure to put forward evidence at different policy and funding tables, often under tight timelines.   A large proportion of health and social services and programs in Aboriginal communities in Canada are funded year by year, with onerous annual reporting requirements that have been criticized by the auditor general as excessive (Mayne J., 2003).

These reporting processes tend to marginalize Aboriginal ways of knowing by focusing on accountability of funds rather than ongoing community planning and evaluation (Smylie J., Anderson I., Ratima M., Crengle S., & Anderson M., 2006a). This can distract from planning and evaluation that is directly accessible, relevant, and useful from a local community service enhancement perspective. Concept mapping helps address this gap by supporting the exploration of complex ideas in a short period of time whereby participants themselves are driving the data collection, analysis and interpretation processes.

Important lessons can be gleaned from the three distinct community maps. Firstly, the Métis in Ottawa generated a map in which most clusters were lying on top of one another. There are several possible explanations for this. Firstly, there may have been a need for more sorters and raters in the Métis community because of greater variance and heterogeneity in this population. Specifically, Ottawa Métis represent a culturally diverse group of people, the large majority of whom have migrated to Ottawa from elsewhere in Ontario and Western Canada (MacDougall B., 2012). In addition, Ottawa Métis are more dispersed than in other parts of the country, more difficult to identify visually and few participate in Métis-specific events (Smylie J., Métis Nation of Ontario, Wellington P., & Adomako P., 2008). These characteristics may have contributed to the variation in the participants sorting and rating and thus made it more challenging to generate map clusters. There may be limitations to capturing the diversity and richness of individual narrative and experiences through concept mapping since it does blend or "average" individual input into a collective picture.

Overall, map clusters centered on the social determinants of health were those most highly rated on each of the community's maps. This makes sense given that for Aboriginal people, ill health is directly linked to social determinants of health including colonization, cultural suppression, family and community dislocation chronic unemployment, poverty, lower education attainment, and unhealthy environments (National Aboriginal Health Organization (NAHO), 2003). Poverty, housing and socio-economic needs were also rated highly and we know that disparities in social determinants of health such as income insecurity, unemployment, low levels of education, decreased food availability, and inadequate housing among the Aboriginal population as compared to non-Aboriginal Canadians are exacerbated with urban residence (Statistics Canada, 2008). After completing the Our Health Counts survey in each of the three sites, the results not only confirmed Census findings, but health and social inequities

reported by First Nations in Hamilton, Inuit and Métis in Ottawa were even more striking and showed greater disparity than that of the Census (Smylie J. et al., 2011a; Smylie J. et al., 2012). In all three communities, both proximal determinants of health such as the physical environment, employment and education as well as more distal, Indigenous-specific determinants such as colonialism, social exclusion, trauma and recovery and lack of government responsibility emerged (Loppie Reading C. et al., 2009). Clearly, both historical and present day experiences need to be addressed when considering health issues in this population.

Mental and emotional well-being was also of high importance across the communities. Again, this is not surprising as rates of suicide, depression, family violence and substance abuse, are significantly higher in many Aboriginal communities as compared to the general population (Health Canada, 2002; Chandler M.J. et al., 1998; Indian and Northern Affairs Canada, 1996). Interestingly, however, chronic diseases and specific illnesses or disabilities did not surface as top priority health issues facing these populations. Chronic diseases such as heart disease, diabetes and cancer in addition to Fetal Alcohol Syndrome, obesity, HIV and Hepatitis C did emerge during the brainstorming with First Nations in Hamilton and were placed in the cluster labeled "Out of Balance". For the Métis in Ottawa, diabetes, obesity and allergies were statements within the "Health Promotion and Nutrition" cluster. Finally, for the Inuit in Ottawa, the only condition that was voiced during the brainstorming was allergies and was placed in the cluster "Keeping Warm and Safety". Again, specific conditions and physical health at the individual level were considered within a broader context of wellness and related social determinants of health. This conceptualization of health priorities is in tension with existing Aboriginal policy, service provision and research, which is very much focused on chronic disease (Young T.K., 2003; Institute of Aboriginal Peoples' Health (IAPH), 2006). The outcomes of concept mapping in each of the three communities laid the conceptual foundation for the development of health surveys that go beyond individual-level factors and look at larger social constructs impacting each of the three populations.

The First Nations, Inuit and Métis communities involved in the Our Health Counts project all developed a health assessment survey tool that reflected their unique cluster maps. The instruments themselves were well received by the communities and implemented successfully with urban First Nations in Hamilton and urban Métis and Inuit in Ottawa. Concept mapping was an effective method for addressing the goals of this study as it embraced

the diverse historical, cultural, political and social contexts of the three participant communities and contributed to theoretically sound domains for each health survey.

There are a number of study limitations that should be addressed. First, given the high level of literacy needed to complete the concept mapping process, there were some challenges, particularly in the Inuit community where sessions needed to be bilingual. Secondly, the qualitative purposive sampling technique generated a relatively small number of participants for each of the concept mapping activities. As a result of smaller sample sizes, the study populations may not have been representative of all the community health organizations and stakeholders among Hamilton First Nations, Ottawa Inuit and Ottawa Métis populations. Another limitation with concept mapping is that although cluster maps reveal similarities between cluster items, maps do not provide any data on the relationships between clusters, which would have perhaps shed more light on why there was so much overlap of clusters in the Métis community map.

Traditionally, epidemiological narratives have portrayed the Aboriginal community as being sick and miserable which contributes to the overall public's understanding and the social construction of Aboriginal identity (O'Neil J.D. et al., 1998). Such portraits generate an image of communities that are ill and disorganized and can reinforce dependency and the power of paternalism (ibid). Research institutions and communities themselves are resisting this type of narrative and developing tools, guidelines and principles for more ethical, inclusive and community-based research (CBR) on health issues. Participating communities were able to articulate concepts of health that challenged existing illness-based narratives – naming instead external social conditions and inequities as core concepts that inform their understandings of their health. Of importance, each set of community cluster labels not only described these externally imposed challenges but also conveyed pathways for individual and community resistance and change.

Concept mapping is a mixed methods approach that provides a structure for multiple voices to be heard and supports community engagement in developing a visual representation of community knowledge and priorities. The findings discussed here have tremendous policy and programming implications for urban Aboriginal people. Finally, the concept maps informed the development of survey tools, which will generate population health data that have previously not been available for these populations.   Unlike research and data processes that maintain social

exclusion of Aboriginal people, this study will serve as a model that places community at the centre and reduces social inequities.

Chapter 6 Paper #2: Using Respondent Driven Sampling to Unmask the Disparities in Social Determinants of Health for Urban First Nations People Living in Hamilton, Ontario

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Abstract

Background: Population based health information on urban Aboriginal populations in Canada is limited due to challenges with the identification of Aboriginal persons in existing health datasets. Compared to non-Aboriginal Canadians, First Nations, Inuit, and Métis populations experience ongoing disparities in social determinants of health such as income insecurity, unemployment, low levels of education, decreased food availability, and inadequate housing and these disparities are exacerbated with urban residence. Respondent Driven Sampling (RDS) is a modified chain-referral sampling approach that is increasingly used to recruit participants from hard to reach populations. By implementing RDS, the Our Health Counts study in partnership with De dwa da dehs ney>s Aboriginal Health Access Centre (DAHC) generated a representative sample of First Nations individuals living in Hamilton, Ontario.

Methods: The RDS process was initiated through the selection of seeds. Seeds represented a group of individuals in the community who met the study eligibility criteria: First Nations adults over 18 years of age currently living in the city of Hamilton. Starting with seeds, all participants completed the health assessment survey and when eligible, a survey about a child in the household and received 3-5 coded coupons to refer members of their social network into the study. Analysis of data was conducted using a RDS-specific tool in order to generate population proportion estimates for social determinants of health including income, mobility, overcrowding and food availability. Using participants' health card numbers, a linkage to the Institute of Clinical Evaluative Sciences (ICES) database allowed for income quintile data to be generated.

Results: The total RDS sample among First Nations in Hamilton was comprised of 790 community members, including 554 adults and 236 children. Among the First Nations individuals in Hamilton, 78.9% of participants were recruited via referral trees originating from two seeds. These referral chains had 19 and 32 waves of recruitment each, suggesting that the final sample is independent from the original seeds with respect to key characteristics and behaviors. Population based estimates of social determinants of health and adjusted income quintile data comparing First Nations individuals residing in Hamilton with the general Hamilton and Ontario populations reveal significantly high rates of poverty and unstable living conditions among urban First Nations people in Hamilton.

Conclusions: RDS is a useful recruitment method in Aboriginal contexts as it builds upon existing social networks, is community driven and successfully identified a population-based cohort of urban First Nations people living in Hamilton. RDS estimates of household income, housing and food security illustrate striking disparities in social determinants of health between First Nations individuals and the general population of Hamilton, Ontario.

Introduction

According to the 2006 Census, over 60% (150,570 people) of Aboriginal people living in Ontario live in urban areas. In Canada, nearly seven out of ten Métis live in urban areas and about three out of every four people in the off-reserve First Nations population live in urban areas (Statistics Canada, 2008). First Nations people have historically, been dislocated from their original homelands and may constitute diasporic, heterogeneous communities in urban areas (Canadian Institute for Health Research (CIHR), 20097). Specifically, an increasing number of First Nations individuals are moving to urban centres to seek better housing, employment and health care (National Aboriginal Health Organization (NAHO), 2003). According to the Canadian Census that First Nations, Inuit, and Métis populations experience ongoing disparities in social determinants of health such as income insecurity, unemployment, low levels of education, decreased food availability, and inadequate housing compared to non-Aboriginal Canadians and that these disparities are exacerbated with urban residence (Statistics Canada, 2008).

Despite the growing size of the urban Aboriginal population in Canada, accessible and culturally relevant population health data for this population are almost non-existent. From a public health perspective, this near absence of health assessment data for these populations is extremely concerning, particularly given the known disparities in the social determinants of health. While census data do exist, there are serious deficits in population health measures. Some of the reasons behind this deficiency are due to limitations in the current health information system and data collection processes with respect to Aboriginal peoples. For example, there is not a systematic or consistent mechanism for individuals to self-identify as First Nations, Métis or Inuit in Canadian population surveys. Sampling frames are often biased and comprise non-random subpopulations such as lists of members or clients of particular programs and services in the community. When urban Aboriginal people have been included in census based national surveys (such as the Canadian Community Health Survey) these surveys are underpowered and often First Nations, Inuit, and Métis data cannot be successfully disaggregated (Smylie J. et al., 2010; Smylie J. et al., 2011b; Smylie J. et al., 2006b). Additionally, studies based on Census data show that a significant number of Aboriginal people move from rural and reserve areas to cities, and back and forth as well as within and among

cities (Graham K.A. et al., 2002). These factors make it difficult to get a firm count of the Aboriginal population of a city.

At the national level, the continued inability to identify Aboriginal peoples in healthcare databases leads to very poor coverage of Aboriginal populations in Canada, with a specific paucity of health information for non-registered First Nations, Métis, and Inuit living in urban areas. Provincial and territorial systems generally do not collect ethnic specific utilization data, and their ethnic flags for vital statistics are inconsistent or absent (Anderson M. et al., 2006). The federal government's recent decision to cancel the long form of the Canadian national census will further challenge the ability of researchers and communities to identify and address social inequities across ethnic groups and will widen the existing policy vacuum (Collier R., 2010). The main objective of the Our Health Counts (OHC) project was to work in partnership with Aboriginal stakeholders in addressing these disparities and to generate a culturally relevant, representative baseline health data set for three urban Aboriginal communities in Ontario, Canada.

In the absence of an accessible and accurate population based sampling frame for urban Aboriginal people, we implemented respondent driven sampling (RDS) for the OHC study. RDS, like other chain-referral approaches relies on members of a population to recruit their peers. However, RDS challenges other methods because it allows for the bias in the sampling process to be estimated (Heckathorn, 2002). Another aspect of RDS that differentiates it from snowball and other traditional chain-referral methods is the dual incentive structure. Specifically, respondents receive an incentive not only for the time they spend responding to the survey, but also for each eligible participant they recruit into the study.

There is limited literature on RDS specifically in Indigenous contexts; however there is evidence that links the success of RDS to the strength of social networks and relationships (Abdul-Quader A., Heckathorn, & Saidel T., 2006). Indigenous knowledge is holistic, relational and embraces a fluidity that allows for constant growth and change (Greenwood M., 2005; Ermine W., 1995). As described by Indigenous scholar Margo Greenwood, Aboriginal citizenship values the group over the individual, thereby establishing models of kinship whereby everyone has the right to give and receive according their own choices (Greenwood M., 2005). We hypothesized that RDS would be an appropriate and effective sampling methodology as it

builds on social networks and would therefore draw on existing kinship systems known to be present in Indigenous communities (Smylie J. et al., 2009).

RDS is based on two observations: equilibrium and the sampling process. The statistical theory is that if the chain-referral process consists of enough waves or cycles of recruitment, the composition of the final sample with respect to key characteristics and behaviors will become independent of the seeds from which it began. The implication is that if recruitment chains are sufficiently long, the selection of seeds becomes irrelevant, so lengthening recruitment chains provides the means for overcoming bias from the choice of seeds. The point at which the sample composition becomes stable is termed "equilibrium" and is an indication that RDS has been implemented successfully.

The second observation upon which RDS is established is that by gathering information during the sampling process, the means for constructing a sampling frame from which inclusion probabilities can be calculated is established. This, in turn, provides the means to verify that population estimates are unbiased, and to determine the variability of these indicators (e.g., calculate standard errors, confidence intervals, and design effects). The success of RDS is contingent on the collection of the following information for each participant recruited in the study:

1. *Who recruited whom?* This provides the basis for controlling for bias introduced by the tendency of subjects to recruit those like themselves. Therefore, an important element in the RDS research design is documenting recruiter/recruit relationships. Tracking the connection between recruiter and recruit allows for the generation of a recruitment tree and contributes to the analysis of recruitment dynamics, which are indicators of a successful RDS sample.

2. *How well connected is each respondent within the target population, that is, what is the subject's personal network size?* Information on how many persons each subject knows who fit the eligibility criteria for the study provides the means for controlling for bias toward over sampling those with larger personal networks. Social network size is an

essential variable in RDS analysis when calculating population estimates for health, social and behavioural characteristics of interest.

3. *Do the recruiter and recruit know one another, or are they strangers?* Collecting information on the nature of the relationship between recruiter and recruit illustrates the different ties and connections that make up the social network of the population of interest.

The results presented here pertain specifically to the urban First Nations population in Hamilton where the organizational project lead was De dwa da dehs ney>s Aboriginal Health Access Centre (DAHC). We conducted this research in order to establish population-based estimates for determinants of health including income, mobility, over crowding and food security. Through a data linkage with the Institute for Clinical and Evaluative Sciences (ICES), we also produced RDS-adjusted income quintile data.

Methods

Study Population

In 2006, the total Aboriginal population by ancestry in Hamilton was 13,735, which represented 2.8% of the overall population of the city (497, 395) (Statistics Canada, 2007b; Statistics Canada, 2008). The census count, however is an under-representation as it does not capture persons who choose not to participate in the Census for personal and/or political reasons; persons who participate in the census but choose not to identify as First Nations or do not identify with any of the options provided under 'ethnicity' in the census; and persons who are homeless or without a permanent address (Anderson M. et al., 2009).

The sample size for this study was calculated using the formula provided by Salganik for RDS, who recommends that an RDS sample size should be twice as large as that would be needed under simple random sampling (Salganik M.J., 2006). Based on this formula, the Our Health Counts study aimed to recruit 500 First Nations adults and 250 children.

Survey Tool

Community concept mapping was implemented to develop a community specific adult and child health survey for First Nations in Hamilton. The survey was comprised of 8 domains covering areas such as sociodemographics, physical, mental, and emotional health problems, First Nations identity and impacts of colonization, access and barriers to care, as well as a separate section pertaining specifically to child health (See Appendix F). Survey tools were piloted with First Nations community members who were otherwise ineligible for the survey (i.e. their residence was outside of the city of Hamilton).

ICES Data Linkage

The Institute for Clinical Evaluative Sciences (ICES) is a non-profit research organization that contributes to the effectiveness, quality, equity and efficiency of health care and health services in Ontario, Canada. ICES can anonymously link data from a variety of different sources, including population based surveys and major clinical and administrative health databases in order to obtain a comprehensive understanding of health care issues. During the consent process, participants were provided information about ICES and then were given a choice to opt in or out of the ICES data linkage for themselves or their children. First Nations adult and child participants in the OHC study were identified in the larger ICES database using a deterministic linkage based on their Ontario health card number, date of birth and name. In order to protect the confidentiality of study participants, this linkage was done internally at ICES, by ICES staff.

Data Collection

The RDS process was initiated through the selection of seeds. Seeds represent a diverse and dynamic group of individuals in the community who are part of a broad social network and who meet the study eligibility criteria. Inclusion criteria for participation in the study included adults who resided within the geographic boundaries of the City of Hamilton and self-identified as having First Nations/Native/Indian identity. Adults were defined as persons 18 years of age and older or persons younger than the age of 18 years who were parents. Parents or custodial relatives/guardians completed the child survey for all children who resided with the adult and were under the age of 14 years.

With the help of community partners and other First Nations key informants (i.e. Aboriginal community outreach workers); potential seeds were identified in the community. Efforts were made to select seeds across various socioeconomic strata and from diverse networks within the First Nations community. For example, seeds were identified in the student population, among the steel workers union, among artists, elders, housing and social assistance providers as well as members of local Aboriginal organizations and boards. A group of 10 potential seeds attended a lunch and learn session where the research team explained the study and its objectives. Six attendees agreed to become seeds. Five of the six seeds produced referrals within the two weeks leading up to the December 2009 holiday closure at DAHC. In February 2010, in order to increase the number of completed child surveys, two additional seeds were added specifically targeting families with children.

All study participants, including seeds, provided informed consent and then completed the health assessment survey after which they received 3-5 coded coupons to refer a member of their social network into the study. Each of their recruits who met study criteria then completed the survey and received 3-5 additional coupons to recruit their peers and so on. Following the holiday closure of DAHC, the number of distributed coupons per recruit was increased from 3 to 5 in order to generate more recruitment momentum. Participants received a monetary reimbursement for their time and participation. This consisted of $20 for completion of the survey and an additional $10 for every person recruited into the study.

All members of the study team were from the Aboriginal community, living in the general vicinity of the city of Hamilton. In addition, study recruitment and interviews took place in an Aboriginal community centre, creating a neutral and comfortable space in which to recruit and interview study participants.

Analysis

Analysis of recruitment chains and recruitment dynamics were conducted in order to determine if the sample reached equilibrium, a state in which the final sample is independent from the bias around seed selection. These analyses are generated using specific recruitment information that was entered into custom RDSAT software (volume 6) (Volz E., Wejnert C., Degani I., & Heckathorn, 2007). Each study participant was asked to provide information on the size of their social networks (how many First Nations people they knew by name who lived in

the city of Hamilton) and the relationship to the person who gave them the coupon (relative; girlfriend/boyfriend, partner or spouse; friend; acquaintance; or stranger). In addition, the interviewers recorded the number of the coupon presented by each individual and the numbers of the coupons they were given to recruit their peers. All of the population estimates and 95% confidence intervals presented in this paper were adjusted for RDS using RDSAT software.

Results

Recruitment Dynamics

Among the RDS sample of First Nations in Hamilton, 78.9% of participants were recruited via referral trees originating from two seeds (see figure 1). The length of both of these recruitment chains is long enough that both chains were able to overcome the original sampling bias. This usually happens after 6 or 7 waves of recruitment (Wejnert C., 2009). These two recruitment chains had 19 and 32 waves of recruitment each. The relationship between recruiter and recruit (according to recruit) was "friend" in 46% of recruitments, "relative" or "boyfriend/girlfriend" in 42.6% of recruitments, "acquaintance" in 8.6% of recruitments, and "stranger" in 3% of recruitments. The average network size varied among participants, with a mean of 46.6, a median of 20, and a range of [1, 2000]. A total of 49% of respondents recruited others into the sample. The mean number of recruitments for all sample members was 0.96; the mean number of recruitments among those who recruited was 1.96.

Figure 1. Recruitment Tree of First Nations in Hamilton, Our Health Counts
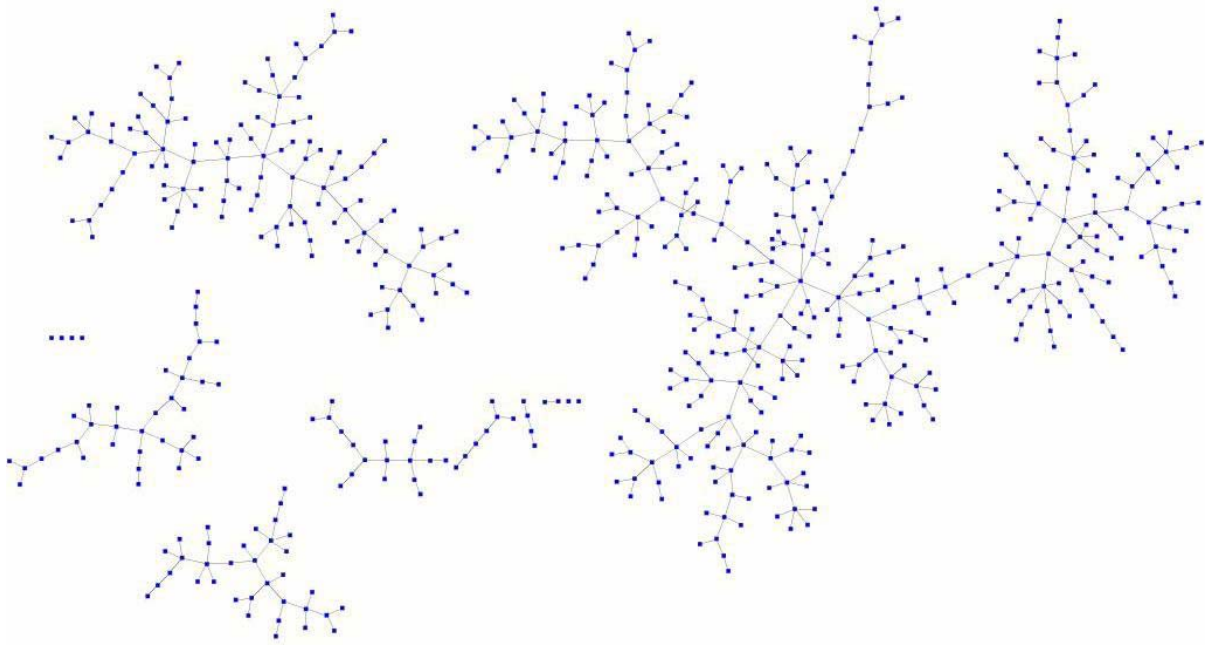
Sociodemographics

The OHC First Nations Hamilton sampling was extremely effective and efficient. Over a period of four and a half months a total of 790 persons were recruited, including 554 adults and 236 children. The study sample was comprised of 60% men and 40% women. For men, about a third of the population fell in each of the following age categories: 18-34 years (34.5%), 35-49 (35.2%) years and 50+ (30.3%) years. The female population however was younger, with 47.7% between the ages of 18-34, 36.3% between 35-49 years and 16% over the age of 50.

The first domain of the health assessment survey covered sociodemographics including housing, socioeconomic status and food security. Data gathered from this section of the survey are presented here and displayed in Table 1. In addition, through the data linkage with ICES, a comparison of income quintiles between the OHC study sample, the city of Hamilton and the province of Ontario was also made possible (Table 2). Overall, these results clearly indicate the cycle of poverty experienced by this study population.

When asked to indicate the source(s) of the total income for all household members in the past 12 months, the following results emerged: wages and salaries (28.2%), income from self-employment (7.7%), employment insurance (9.6%), Child Tax Benefits (17%), Provincial or municipal social assistance or welfare (e.g. ODSP, Ontario Works) (69.2%), child support (3%), any other income source (13.3%). Clearly, this population is relying heavily on social assistance.

In addition to sources of income, we also determined personal income for the year ending on December 31st, 2008. Specifically, 18.3% earned less than $4,999, 23.1% earned between $5,000 and $9,999, 21.9% earned between $10,000 and $14,999, 14.8% earned between $15,000 and $19,999 and 21.9% earned over $20,000. As a comparison, according to the 2006 Census, 15% of residents of the city of Hamilton aged 15 and older earned less than $5,000, 9% earned between $5,000 and $9,999, 10% earned between $10,000 and $14,999, 9% earned between $15,000 and $19,999 and 57% earned over $20,000 (Social Policy and Research Council of Hamilton, Internal Data).

There were also high levels of mobility reported among population. Only 10% of the population had no moves over the past 5 years. Over 20% of the population had moved 2 times in the past five years, while 41% had moved between 3 and 5 times in the past 5 years and 10% had moved 6 to 10 times in the past 5 years. These numbers are very high compared to total urban populations in Canada. For example, according to the 2006 Census, among all people living in the city of Hamilton, 60% had lived at the same address 5 years ago and 87% had lived at the same address 1 year ago (Statistics Canada, 2010). With respect to the total urban Aboriginal populations in Canada, the 2006 Census revealed that 25% of the total urban Aboriginal population has moved at least once in the year before the census (Indian and Northern Affairs Canada, 2010).

Following Statistics Canada standards, overcrowding was calculated by dividing the number of rooms in each household (excluding bathroom) by the number of people residing in the home. Using the Statistics Canada definition of crowded housing as more than one person per room, 73.7% of the First Nations population lived in crowded conditions. Specifically, 27.7% of the population were living with less than or equal to 1 person per room, 46% were living with more than 1-2 persons per room and 26.3% were living with more than 2 persons per

room. The general Canadian population reported a 3% overcrowding rate in the 2006 Census (Statistics Canada, 2008).

Participants were asked to describe food availability for themselves and their households. A total of 22% of the First Nations population in Hamilton reported that they sometimes or often did not have enough food to eat. Over half of the sample felt that they and others had enough to eat, but not always the kinds of food you wanted and 27% felt that they and others always had enough of the kinds of food they wanted to eat.

Table 1. Income, Mobility, Overcrowding and Food Security Indicators, First Nations Adults, Hamilton, Ontario

Indicator		Col%	95% CI
Income sources for household			
	Wages and salaries	28.2	[22.1, 34.2]
	Income from self-employment	7.7	[4.3, 11.7]
	Employment insurance	9.6	[5.4, 14.3]
	Child Tax Benefit	17	[12.4, 21.8]
	Provincial or municipal social assistance or welfare (e.g. ODSP, Ontario Works)	69.2	[63.1, 75]
	Child Support	3	[1.1, 4.6]
	Any other income support	13.3	[9.2, 17.6]
Individual annual income			
	$0-4,999	18.3	[13.4, 24.8]
	$5,000-5,999	23.1	[17.1, 28.5]
	$10,000-14,999	21.9	[16.3, 27.6]
	$15,000-19,999	14.8	[10.7, 20]
	$20,000+	21.8	[16, 27.6]

Mobility			
	No moves in past 5 years	10.2	[6.2, 14.8]
	1 move in past 5 years	15.5	[10.5, 20.6]
	2 moves in past 5 years	20.2	[15.4, 26.4]
	3-5 moves in past 5 years	41.1	[35, 48.6]
	6-10 moves in past 5 years	10.4	[5.7, 13.4]
Overcrowding			
	1.00 <=1 persons per room	27.7	[21.6, 33.8]
	2.00 1-2 persons per room	46	[40.5, 54.3]
	3.00 >2 persons per room	26.3	[19.7, 30.8]
Food security			
	You and others always had enough of the kinds of food you wanted to eat	26.7	[21.1, 32.8]
	You and others had enough to eat, but not always the kinds of food you wanted	51.5	[45.3, 58]
	Sometimes or often did not have enough to eat	21.8	[16.5, 27]

The following table describes income quintile by census postal code produced for First Nations individuals in the City of Hamilton and the province of Ontario. Again, the estimates for income quintile were adjusted using RDSAT software. Over 70% of the First Nations population fell into the lowest quartile compared to 25% of the general Hamilton population and 20% of the Ontario population. Similarly, 75% of First Nations children fell into the lowest income quartile compared to 26% of the Hamilton population and 20% of the Ontario population. At the higher end of the income scale, we observed that while 15% of Hamilton

residents and 20% of the Ontario population fell into the highest income quartile, only 3% of the study population was earning in this category.

Table 2. Income Quintile for Adults and Children, First Nations in Hamilton, General Hamilton and Ontario Population Comparison

		OHC		OHC RDS-Adjusted		Hamilton		Ontario-10%	
Adults		N	Col%	Col%	95% CI	N	Col%	N	Col%
Income Quintile									
	1-Low	376	71.76	73	[66.5, 79.2]	111,468	25.09	213,212	19.5
	2	85	16.22	11.8	[7.7, 16]	101,200	22.78	216,461	19.8
	3	33	6.3	7.4	[3.6, 10.5]	90,069	20.28	216,614	19.81
	4	13	2.48	4.9	[2.5, 9.8]	75,704	17.04	233,113	20.41
	5-High	7	1.34	3	[1.1, 5.4]	65,375	14.72	220,665	20.18
	Missing	10	1.91	n/a	n/a	391	0.09	3,348	0.31
Total		524	100	100	n/a	444,207	100	1,093,413	100
Children									
Income Quintile									
	1-Low	144	74.23	75.25	[69.9, 80.6]	23,741	25.79	46,102	19.97
	2	30	15.46	15.58	[11.1, 20.1]	18,857	20.49	42,636	18.47
	3	9	4.64	5.4	[2.6, 8.2]	19,030	20.67	46,192	20.01
	4	<5	1.03	1.26	[0.01, 2.7]	16,363	17.78	49,563	21.47
	5-High	8	4.12	2.52	[0.6, 4.5]	13,975	15.18	45,675	19.79

Total		194	100	100	n/a	92,046	100	230,828	100

Discussion

The Our Health Counts project successfully generated an urban health database for the First Nation population of Hamilton, Ontario. Through the application of RDS, a sample of urban First Nations individuals who might otherwise not have participated in mainstream surveys or census was captured. In addition, given the current deficiency in public health information on urban First Nations populations, the statistically rigorous RDS sample allowed for derivation of population-based estimates which can be utilized by local, regional, provincial and federal policy makers as well as urban Aboriginal stakeholders to address social inequities and health disparities facing this community.

Striking levels of poverty were identified by the OHC study. Specifically, among First Nations people living in Hamilton, 78% earn less than $20,000 per year and 70% live in the lowest income quartile neighborhoods compared to 25% of the general Hamilton population. Accompanying high levels of poverty, housing and food insecurity were also highly prevalent among First Nations persons living Hamilton. Over half of the study population had moved at least 3 times in the past 5 years compared to 60% of the general Hamilton population who had been living at the same address for the past 5 years. A similar disparity between the First Nations population in Hamilton and the general Canadian population was observed for overcrowding (74% vs. 3%). These findings echo those presented in the 2007 Urban Aboriginal Task Force (UATF) final report, which documented persistent obstacles with finding affordable housing, obtaining stable and secure employment and accessing appropriate services and resources among urban Aboriginal people (Ontario Federation of Indian Friendship Centres (OFIFC), Ontario Métis Aboriginal Association, & Ontario Native Women's Association (ONWA), 2007). Evidently, despite the efforts of both Aboriginal and non-Aboriginal organizations, there remains a significant amount of unmet basic needs among urban Aboriginal people in Ontario.

For many Aboriginal people, ill health is directly linked to social determinants of health including colonization, cultural suppression, family and community dislocation, chronic unemployment, poverty, lower education attainment, and unhealthy environments (National Aboriginal Health Organization (NAHO), 2003). The Royal Commission on Aboriginal Peoples (RCAP) also identified poverty, despair, poor housing and political alienation as some of the root causes for many of the traumatic mental health problems prevalent in aboriginal communities (Smye V. et al., 2002; O'Neil J.D., 1993). Clearly, both historical and present day experiences need to be addressed when exploring health issues in this population.

In the face of these challenges, it is very important to recognize that many Aboriginal communities are experiencing good levels of health and well-being, demonstrating resilience, celebrating cultural values and actively transmitting cultural knowledge and traditions to younger generations (Kirmayer L.J. et al., 2009). Despite extreme inequities in social determinants of health, First Nations people living in Hamilton also exhibited remarkable cultural continuity and resilience (Smylie J. et al., 2011a). OHC study measures indicated a strong sense of identity among the First Nations population living in Hamilton as well as a strong desire to pass culture and language on to the next generation.#

There were a number of limitations of the study. Firstly, there are some inherent limitations with RDS as a sampling methodology. In reality, the distribution of coupons does not guarantee a random sample of network members (Heimer R., 2005). A recruiter will make an effort to recruit individuals who meet the study inclusion criteria, but also will recruit based on the likelihood of recruits presenting themselves to the study (ibid). Given the economic and social reality of many study participants, individuals who were interested in the study and the potential incentives they could receive were frequenting the Aboriginal community health centre in order to encounter someone they knew who had coupons to distribute. This may have biased the sample; however continuous efforts were made by the on-site study staff in order to encourage participants to distribute their coupons outside of the community health centre and to people who they knew. Finally, our data may represent an under-estimation of First Nations individuals over 60 years old. Perhaps if we had recruited a seed from this age group, we may have sampled more seniors. Despite these limitations, RDS proved to be an advantageous

method for the OHC study. Specifically, respondent driven sampling proved to be an effective tool to recruit an urban Aboriginal population and allowed for the derivation of rigorous population estimates and data linkages that have previously not been possible.

One of the strengths of the OHC study was the development and strengthening of partnerships between provincial Aboriginal organizations, research institutions and government bodies. In addition, data collection, governance and management upheld the ethical and research standards of Ownership, Control and Possession (OCAP) and was implemented within a community-based participatory research framework (Schnarch B. et al., 2004; Smylie J., 2010). Stakeholders have already started to work together across sectors to drive the necessary policy changes towards the improvement of the health and social status of urban Aboriginal people living in Ontario (Smylie J. et al., 2011a). More long-term implications of this research will support the development of RDS as a tool to effectively recruit a larger cohort for longitudinal research with Aboriginal families in Ontario.

Chapter 7 Paper #3: Mental Health, Substance Use and Access to Emotional Supports among an Urban First Nations Population in Hamilton, Ontario

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Abstract

Background: Mental health and substance use have been identified as top health priorities currently facing Aboriginal peoples in Canada, however accessible and culturally relevant population health data for this group are almost non-existent. There is an urgent need for more community centric research and data systems in the area of Aboriginal urban health. Using First Nations adult population data from the Our Health Counts study conducted in Hamilton, Ontario, we aimed to address these knowledge gaps.

Methods: Analysis involved data gathered through Respondent Driven Sampling (RDS) among First Nations adults in Hamilton. RDS uses chain-referral sampling to generate probabilistic population estimates. By analyzing the ties between respondents, one can make inferences about the study population. Prevalence estimates and 95% confidence intervals were generated for diagnosis and treatment of a psychological disorder or mental illness, depression, anxiety, post-traumatic stress disorder (PTSD) and suicide, alcohol and substance misuse, and access to emotional and mental health support.

Results: Of the 554 First Nations adults who participated in the Our Health Counts study in Hamilton, 42% had been told by a health care worker that they had a psychological and/or mental health disorder. Rates of depression, PTSD as well as suicide ideation and attempts were very high. Half of the sample reported marijuana use in the previous 12 months and use of cocaine and opiates was also high. Aside from family and friends, very few First Nations individuals reported having spoken with a professional or service provider about an emotional or mental health problem.

Conclusions: First Nations adults living in Hamilton experience a disproportionate burden of mental health and addictions challenges as well as extreme adversities in the social determinants of health. By working in partnership with urban Aboriginal organizations it is possible to produce policy and service relevant data and address the current deficiency in appropriate mental health and substance misuse services for urban Aboriginal people.

Introduction

In Canada, cycles of family disruption, abuse, colonization, dislocation from traditional lands and outlawing of spiritual practices among First Nations, Inuit, and Métis peoples have led to many health and social inequities. Rates of suicide, depression, family violence and substance abuse, are significantly higher in many Aboriginal communities as compared to the general population (Health Canada, 2002; Chandler M.J. et al., 1998; Indian and Northern Affairs Canada, 1996). The National Aboriginal Health Organization (NAHO) as well as the Assembly of First Nations have identified emotional and mental health as one of the top health priorities currently facing Aboriginal peoples in Canada (National Aboriginal Health Organization (NAHO), 2003). Currently, however, accessible and culturally relevant population health data for urban Aboriginal populations are very limited. This near absence of health assessment data is extremely concerning given the health and social disparities between Aboriginal people and the general Canadian population (Health Canada, 2002; Statistics Canada, 2008). The aim of this research is to fill existing knowledge gaps by generating culturally relevant and accessible population based health information for an urban First Nations community in Hamilton

Prevalence rates of specific psychiatric disorders, diagnosed using culturally validated measures among Aboriginal people are almost non-existent. Existing prevalence data are generally unadjusted and based on service utilization or clinic records, which produces gross underestimates, as many Aboriginal people do not utilize mainstream services (Kirmayer L.J. et al., 2000). Several Indigenous community surveys conducted in Canada and the United States have generated a wide range of prevalence rates of psychiatric disorders. This breadth of resulting data is a result of both existing cultural and historical differences across populations as well as methodological challenges with measuring and diagnosing these illnesses (Kirmayer L.J. et al., 2009).

The First Nations and Inuit Regional Longitudinal Health Survey (RHS), a national, population-based sample administered and governed by the Aboriginal community has generated high quality and culturally grounded evidence, however it is restricted to on-reserve and mostly non-urban populations (Dumont J., 2005). In 1997, the RHS reported that about 18% of on-reserve First Nation and Inuit adult populations surveyed met the criteria for major depression; 27% reported problems with alcohol; and 15% attempted suicide at some time in their lives (First

Nations Centre National Aboriginal Health Organization, 2004). Results from the 2002 RHS indicated that 30.1% of respondents had experienced a time when they felt sad, blue or depressed for two weeks or more in a row, 30.9% reported having suicidal thoughts over their lifetime, and 15.8% reported having attempted suicide at least once in their lifetime (Assembly of First Nations, 2007b). In comparison, the Canadian Community Health Survey (CCHS) does include off-reserve Aboriginal populations in Canada; however it has a higher response bias and is not administered by the community. Results from the 2000/2001 CCHS found that 13.2% of the off-reserve Aboriginal population had experienced a major depressive episode in the past year, a number 1.8 times higher than the non-Aboriginal population (Tjepkema M., 2002).

Suicide rates among certain First Nations and Inuit communities in Canada are alarmingly high (Aboriginal Healing Foundation, 2007; Indian and Northern Affairs Canada, 1996; Kirmayer L.J., 1994). Although there are enormous variations across communities, the overall suicide rate among First Nation communities is 3-5 times that of the total Canadian population (Aboriginal Healing Foundation, 2007; Health Canada, 2001b). Again, these data must be interpreted with caution as there are two potentially significant sources of error which must be considered: First, that suicide deaths are often under-reported and classified as accidental deaths and, second that accurate data on whether a person is 'Native' or 'Non-Native' as self-defined or defined by the Census are difficult to collect (Ball and Chandler 1989; Chandler and Lalonde 1998). Marked differences in rates, even in the same geographical area have been noted by Chandler and Lalonde who found that among some 200 Aboriginal communities in British Columbia, there were populations with suicide rates 800 times that of the national average, while for other communities, suicide is virtually unknown (Chandler M.J. et al., 1998). In light of these findings, researchers are starting to explore the relationship between the stresses of colonization and cultural discontinuity and rates of suicide and other indices of trauma (Kirmayer L.J. et al., 2000; Chandler M.J. et al., 1998). It appears that the presence of community factors such as evidence that bands have taken steps toward claiming Aboriginal title to land, presence of self-governance, community control over health services and the establishment of official cultural facilities, are associated with lower levels of suicide (Chandler M.J. et al., 2009). Although further exploration is needed, there is growing support for the importance of community and cultural factors in studies on Aboriginal concepts of mental health and suicide (Kirmayer L.J. et al., 2000; Chandler M.J. et al., 1998).

Related to the lack of available and representative data, is a great need for urban Aboriginal mental health and addiction services. The current mental illness service delivery model has strong psychiatry and biomedical traditions and is largely absent of Indigenous knowledge and experiences. The biomedical model is largely focused on individualized interventions as opposed to a more holistic, Aboriginal model of wellness that involves the physical, emotional, spiritual and mental aspects of a person who is always in connection with his or her community and family as well as his or her natural environment (Adelson N., 2005). Mainstream biomedical healthcare as it has evolved in relation to Aboriginal communities has been heavily influenced by a century of internal colonial politics (ibid). Furthermore, the system itself is flawed with racist overtones and consists of providers who lack training in more inclusive and accessible approaches to mental health care and healing (Tang S.Y. et al., 2008).

Throughout the major urban centres across Canada, there are few agencies that offer a continuum of mental health care designed specifically for delivery to the Aboriginal population. One urban-based example is Anishnawbe Health Toronto (AHT), an accredited community health organization whose mission is "to improve the health and well being of Aboriginal People in spirit, mind, emotion and body by providing Traditional Healing within a multi-disciplinary health care model" (Anishnawbe Health Toronto, 2010). Given the diversity of the Aboriginal population accessing services at AHT, care delivery is provided in Cree, Ojibway and English. AHT exposes its clients to a historical perspective and provides opportunities to learn about traditional teachings, healing and practices as way to shed light on current understandings of political, social and economic situations (Smye V et al., 2001; George P. et al., 1993). Another example is the Aboriginal Alcohol and Drug Worker Program (AADWP) offered in nine Friendship centres in urban settings across Ontario. The AADWP provides a culturally appropriate system of addictions treatment services such as talking circles, sweats, and traditional teachings and referrals to healing lodges and treatment centres for urban Aboriginal people with alcohol and/or drug problems.

Given the almost non-existent population-based mental health data for urban Aboriginal people in Canada, the goal of this research was to address this knowledge gap in the context of urban First Nations people living in Hamilton, Ontario. Respondent Driven Sampling (RDS) is a fairly new recruitment method for urban Aboriginal populations, however it was hypothesized that it would be an effective sampling tool because it builds on the existing strength of social

networks and it allows for the bias in the sampling process to be estimated and can therefore generate unbiased estimates of a population's composition (Heckathorn, 2002). This study was nested within the Our Health Counts project whose main objective was to work in partnership with Aboriginal stakeholders in order to generate a culturally relevant, representative baseline health data set for three urban Aboriginal communities in Ontario, Canada. The results presented here pertain specifically to the urban First Nations population in Hamilton and analysis will focus specifically on mental health outcomes as a key priority identified by the communities involved. The organizational project lead in Hamilton was De dwa da dehs ney>s Aboriginal Health Access Centre (DAHC).

Methods

Respondent Driven Sampling

In the absence of an accessible and accurate population based sampling frame for urban First Nations, respondent driven sampling (RDS) was implemented. RDS is a chain-referral sampling approach that is increasingly being used to recruit samples from 'hidden' populations (Heckathorn, Seeman, Broadhead, & Hugues, 2002; Frost S.D.W. et al., 2006). RDS, like other chain-referral approaches, is based on the assumption that group members can efficiently recruit other group members; however it challenges other methods because it allows for the bias in the sampling process to be estimated (Heckathorn, 2002). The sampling frame in RDS is based on special information collected from the study participants, specifically: who recruited whom, each respondent's personal network size and whether or not the recruit and recruiter know each other or are strangers. This information about the properties of the social network connecting respondents is used to generate estimates about the population. RDS is concerned with the relationship between recruiters, so by analyzing the ties between respondents, one can make inferences about the population of respondents.

Another aspect of RDS that differentiates it from snowball and other traditional chain-referral methods is the dual incentive structure. Specifically, respondents receive an incentive not only for the time they spend responding to the survey, but also for each eligible participant they recruit into the study. For more details on the application and success of this methodology for this research project, see Firestone et al. X, 2012.

Data Collection

The RDS process was initiated through the selection of seeds. Seeds represent a diverse, dynamic group of individuals in the community who are part of a broad social network and who meet the study eligibility criteria. Inclusion criteria for participation in the study included adults who resided within the geographic boundaries of the City of Hamilton and self-identified as having First Nations/Native/Indian identity. Adults were defined as persons 18 years of age and older or persons younger than the age of 18 years who were parents. Parents or custodial relatives/guardians completed the child survey for all children who resided with the adult and were under the age of 14 years.

With the help of community partners and other First Nations key informants, a total of 9 seeds were identified and agreed to participate in the study. All study participants including seeds provided informed consent and then completed the health assessment survey after which they received 3 coded coupons to refer a member of their social network into the study. Each of their recruits who met study criteria then completed the survey and received 3 additional coupons to recruit their peers and so on. On January 6, 2010, following the Christmas and New Years holiday closure of DAHC, the number of distributed coupons per recruit was increased from 3 to 5 in order to generate more recruitment momentum. For participants who received 3 coupons during the first 4 weeks of recruitment, it was not possible to return for an additional 2 coupons. Participants received a monetary reimbursement for their time and participation, which consisted of $20 for completion of the survey and an additional $10 for every person recruited into the study.

RDS Analysis

Demographics of the study population, rates of mental health disorders and substance misuse as well as associated risk behaviours were analyzed. All data were adjusted for RDS using custom RDSAT software (volume 6) (Volz E. et al., 2007). RDS generates population estimates which are then bootstrapped to generate standard errors. The RDS methodology anticipates that personal networks are not randomly distributed, and therefore adjusts for small to moderate levels of network clustering (people having ties to others like them), in the form of post-sampling weights.

Results

Sociodemographics

Over a period of four and a half months a total of 790 people were recruited, including 554 First Nations adults and 236 First Nations children. RDS worked effectively and efficiently among First Nations individuals in Hamilton. Among the RDS sample of First Nations people in Hamilton, 78.9% of participants were recruited via referral trees originating from two seeds, which recruitment chains long enough that both chains were able to overcome the original sampling bias. The study sample was comprised of 60% men and 40% women. For men, about a third of the population fell in each of the following age categories: 18-34 years (34.5%), 35-49 (35.2%) years and 50+ (30.3%) years. Overall, the female population however was younger, with 47.7% between the ages of 18 and 34 years, 36.3% between 35 and 49 years and 16% over the age of 50 years.

Mental Health

When participants were asked how they would rate their mental health compared to other people they knew, well over half of First Nations participants felt their mental health was excellent or good. A striking 42% of First Nations adults reported having ever been told by a health care worker that they had a psychological and/or mental health disorder (Table 1). Among those who had been told they had a psychological and/or mental health disorder, most were told under the age of 35, the majority were taking medication for this disorder and when stratified by age, we found that individuals between 35 and 49 years of age were more likely to be taking medication than their younger counterparts between 18 to 34 years old (73% [57.4, 82.8] vs. 32.7% [19.8, 46.3]). For over half of this population, having a psychological and/or mental health disorder was limiting the kinds of activity that they could do (Table 2).

Among First Nations adults in Hamilton who reported experiences of discrimination because of an emotional or mental health problem, there was a trend to suggest that women were more likely to have experienced discrimination in this context as compared to men (16.1% [8.9, 23.5] vs. 7.9% [4.6, 13]). For many participants, experiences of discrimination because of an emotional or mental health problem prevented or delayed them from seeking health care for it (Table 2).

Table 1. Self-rated Mental Health and Prevalence of Diagnosed Psychological or Mental Health Disorder among Hamilton First Nations Adults, Our Health Counts Study

Indicator	Col%	95% CI
Rate mental health compared to others:		
Excellent	21.4	[16.1, 27]
Good	42.9	[37.2, 49.9]
Fair/Poor	35.7	[28.7, 41.8]
Psychological disorder	41.7	[35, 48.8]

Table 2. Age of Diagnosis, Current Medication/Treatment, Limited Activity, Experiences of Discrimination and Delay in Accessing Care Among Hamilton First Nations Adults Diagnosed with a Psychological or Mental Health Disorder, Our Health Counts Study

Indicator	Col%	95% CI
Age of diagnosis		
<18 years old	29.5	[19.5, 38.3]
18-35 years	42.6	[32.8, 55.7]
>35 years	27.9	[17.7, 37.2]
Taking medication for psychological disorder	55.1	[44.5, 64.9]
Receiving treatment	21.9	[12.4, 28.8]
Psychological disorder has limited activity	50.9	[40.2, 60.5]
Experienced discrimination because of an emotional or mental health problem	11.3	[7.6, 15.7]
Discrimination prevent or delay you from getting health care for it	41.8	[24.9, 60]

Depression, Anxiety, PTSD and Suicide

We implemented the Kessler Psychological Distress Scale K-10 in order to assess depression and anxiety symptoms among study participants. The Kessler Psychological Distress Scale (K10) was initially developed in 1992 for a U.S. population surveys to measure the non-specific aspects of psychological distress (Kessler R.C. et al., 2002). The K-10 Psychological Distress scale has been used extensively in population based studies, mainly in the U.S. and Australia and is well established as a reliable and valid tool in diverse contexts (Andrews G. & Slade T., 2001; Kessler R.C. et al., 2002; Slade T., Grove R.., & Burgess P., 2011). Analyses of the sensitivity and specificity of the K-10 also support the use of this screening instrument to appropriately identify likely cases of anxiety and depression (ibid).

As indicated by scholars in the field (Andrews 2001, Kessler 2002), an individual's total score can be broken down into four categories: low range (10-15), moderate range (16-21), high range (22-29) and very high range (30-50). Results for First Nations adults are provided in Table 2. Those individuals who fall into the high and very high range would likely be diagnosed with anxiety and/or depression.

The Post-Traumatic Stress Disorder (PTSD) screening tool we used was the Primary Care PTSD Screen (PC-PTSD) (Prins, Ouimette, Kimerling et al., 2003). Specifically, First Nations adults were asked if they had ever had any experience that was so frightening, horrible, or upsetting that, in the past month: they had nightmares or thought about it when they did not want to, tried hard not to think about it or went out of their way to avoid situations that reminded them of it, were constantly on guard, watchful, or easily startled, or felt numb or detached from others, activities, or their surroundings. The literature suggests that the results of the PC-PTSD should be considered "positive" if a respondent answers "yes" to any 3 items screening and positive cases should then be assessed with a structured interview for PTSD (Prins et al. 2003). The results are presented in Table 2. More than one third of First Nations individuals in Hamilton reported feelings of trauma related to a past experience in their lives. When we stratified PTSD indicators by gender and age categories, we observed very comparable scores for men and women as well as young and old participants.

Suicide among close friends or family was highly prevalent and a shocking 40% of First Nations adults in Hamilton had ever thought about committing suicide themselves (Table 2). Although gender and age differences were not significant, more women did report having these

thoughts compared to men (46.6% [36.3, 57.3] vs. 36.9% [29.1, 46]) and there is a strong trend indicating that individuals between 18 and 34 years were more likely to have these thoughts compared to participants under 18 years of age (52.8% [41.4, 63.9] vs. 32.7% [22.1, 41.9]). Among those who had thought about suicide, half had attempted suicide, with a similar trend across age groups; more First Nations people over 34 who reported suicide attempts than individuals younger than 34 years of age.

Table 2. Depression and Anxiety, Post-Traumatic Stress Disorder and Suicide, Hamilton First Nations Adults, Our Health Counts Study

Indicator	Col%	95% CI
Psychological Distress Scale		
Low	30.7	[24, 36.8]
Moderate	30.3	[25.2, 37.7]
High	23.7	[17.8, 30]
Very High	15.3	[10.1, 19.7]
PTSD		
Nightmares	34.8	[28, 40.1]
Avoided trauma	43.2	[36, 49.4]
Startled by trauma	41.2	[34, 47.3]
Detached/numb from others or surroundings	36.2	[29.3, 43.5]
"yes" to three or more of the above	34	[27.2, 40.1]
Suicide		
Close friend or family member committed suicide	42.9	[34.9, 48.6]
Self-harm on purpose	28.7	[22.1, 34.7]
Thought about suicide	40.8	[34.5, 47.9]
Attempted suicide	51	[39.9, 61.4]

Alcohol and Substance Misuse

Adjusted self-reported rates of alcohol consumption (5 or more drinks on one occasion in the past 12 months) and substance misuse in the last 12 months, including abuse of illicit and prescription drugs are presented in Table 3. In addition to the drugs listed, we also asked participants about PCP/Angel dust, Acid/LSD/Amphetamines, Inhalants and Ritalin, but the numbers were too small to report. For all drugs, gender differences were not significant and for the majority of drugs, the prevalence of use did not vary substantially across age groups, except for the case of ecstasy where we observed much higher use for persons under 35years of age.

As an indicator of high-risk behaviour associated with drug use, we asked participants about needle sharing. Of the 17% who reported having ever shared a needle to inject any illicit drug, a third had ever shared a needle with anyone including their spouse, partner or friend. Consistent with the literature on injection drug use (Single E., Reimer B., & Symons E., 1999), our data suggest a trend that First Nations men were more likely to have shared a needle as compared to women (21% [14.5, 28.3] vs. 11.6% (5, 19.4]).

Table 3. Substance Misuse, OHC Adults, Hamilton, Ontario

Indicator	Col%	95% CI
5 or more alcoholic drinks on one occasion in the past 12 months:		
Never	26.1	[20.2, 32.1]
Once per month	18.5	[13.8, 23.5]
More than once per month	14.4	[10.2, 20.1]
2-3 times per month	17.5	[12.8, 23.2]
Once per week	6.9	[3.9, 9.6]
More than once per week	16.6	[11.2, 21.7]
Use of drug in the past 12 months		
Marijuana	50.4	[43, 56.9]
Cocaine	19.2	[14, 24.7]

Opiate	18.6	[13.7, 23.9]
Sedative	9.8	[6.2, 14.4]
Ever use needle to inject drug	17.2	[12.5, 22.7]
Shared needle with partner	33.4	[17.4, 49.3]

Access to Emotional and Mental Health Support(s)

As part of the Our Health Counts health assessment, all First Nations adults were asked if in the past 12 months, they had seen or talked on the telephone about an emotional or mental health issue or problem to friends, family or different health and social service providers (Table 4). There was a strong trend to suggest that compared to individuals over 50 years old, younger people (18-34 years) were more likely to have communicated with an immediate family member (43.2% [33.1, 54.4] vs. 27.3% [16.7, 38.8]) and friend (45% [35, 55.2] vs. 26.2 [15.6, 38]) about an emotional problem. In addition, there was a strong trend indicating that women were more likely to have spoken with a friend about an emotional problem compared to men (48% [38.9, 58.4] vs. 30.8% [22.8, 39.1]).

Table 4. Emotional supports, OHC Adults, Hamilton, Ontario

Indicator	Col%	95% CI
Seen or talked on the phone with:		
Immediate family member	36.8	[30.6, 43.2]
Other family member	19.9	[15, 25.1]
Friend	37.8	[31.6, 44.4]
Traditional healer	9.3	[6.2, 13.4]
Family doctor	23.6	[18.5, 28.9]
Psychiatrist	9	[5.3, 12.8]
Community health representative	5.5	[2.7, 8.6]

Nurse	9.3	[6, 12.7]
Counselor	14.7	[10.1, 19.4]
Psychologist	5.6	[3, 8.6]
Social worker	14.8	[10.9, 19.2]
Crisis line worker	5.4	[2.6, 8.7]

Discussion

The goal of this research was to address the current deficiency in Canadian urban Aboriginal mental health and substance use data by generating a representative sample of First Nations individuals living in an urban setting. Through the successful implementation of RDS, population estimates and 95% confidence intervals were produced for mental health, substance misuse and mental health support and access indicators. On the whole, our findings confirm existing community and stakeholder concerns and highlight the elevated levels of emotional suffering experienced by this population.

Close to 40% of First Nations participants scored in the high or very high range of the K-10 Psychological Distress Scale. Although the K-10 is a screening and not a diagnostic tool, individuals who score in these ranges would mostly likely present symptoms for clinical anxiety and depression (Andrews G. et al., 2001; Kessler R.C. et al., 2002). As a comparison, the K-10 Psychological Distress Scale was used to analyze normative data collected from a nationally representative household survey of 8841 adults from Australia in 2007 (Slade T. et al., 2011). Among this sample of Australian, 71.1% scored in the low range, 19.5% scored in the moderate range, 6.9% scored in the high range and 2.6% scored in the very high range. The differences between this mainstream, non-Aboriginal sample and the First Nations individuals in Hamilton are striking. Even compared to the results from the 2008/10 Regional Health Survey among on-reserve and mostly non-urban First Nation, which indicated that 48.9% scored in the low range (0-5), 44.8% scored in the moderate range (6-19) and 6.3% scored in the high range (20 and higher) (The First Nations Information Governance Centre, 2012), the First Nations population in Hamilton is exhibiting more prevalent and serious signs of anxiety and depression. Clearly,

there is a need for further exploration around the urban environment and related challenges with access to housing, a lack of food security and high levels of poverty experienced by this population and their impact on mental and emotional health.

Forced assimilation in Canada has had a serious impact on factors such as identity and mental health of Aboriginal peoples as well as on the dynamics and overall structure of communities, bands and nations (Kirmayer L.J. et al., 2003). It must be recognized that the impacts of historic events and policies on mental health and well-being might have been different for First Nations, Métis and Inuit, with differences manifesting themselves also between communities living on and off-reserve in Canada and in the United States. While there are challenges with defining and evaluating historical trauma, there have been attempts to measure these constructs and generate some empirical evidence to support what has been observed for the past several decades in many communities (Whitbeck L.B. et al., 2004). In Canada, there has been some work around 'Residential School Syndrome', defined as a subtype of PTSD for individuals who attended an Indian residential school or who are closely related to or involved with a person who attended, and which focuses on intense feelings of fear and anger and the tendency to abuse alcohol and drugs (Corrado R.R. & Cohen I.M., 2003). This diagnosis however, is not widely known or approved by the American Psychological Association (Robertson L.H., 2006). The existing literature speaks to the need for more efforts focused on the experiences and knowledge from distinct communities as well as a need to develop and employ appropriate measures of trauma in Aboriginal contexts.

To date, in Canada, no systemic studies have been conducted in order to generate comparable population-based PTSD screening data or prevalence rates for Aboriginal people (Bombay A., Matheson K., & Anisman H., 2009). Findings from a telephone survey of close to 3000 Canadians in 2002 revealed a prevalence rate of lifetime PTSD estimated to be 9.2%, with a rate of current (1-month) PTSD of 2.4% (Van Ameringen M., Mancini C., Patterson B., & Boyle M.H., 2008). Due to variations in screening tools, sample size, time-frame for symptom duration and other characteristics of a population, comparison of epidemiological PTSD data is complicated (ibid). For First Nations individuals in Hamilton, we observed that over a third of the population had experienced past trauma in their lives that was impacting their everyday well-being. As presented elsewhere in the literature, PTSD may be linked to residential school attendance, abuse and family violence, family disruption by child protection services and

transgenerational trauma related to these and other impacts of (Silburn S.R. et al., 2006; Menzies P., 2010; Corrado R.R. et al., 2003). Clearly, PTSD is highly prevalent among First Nations individuals in Hamilton. There is an urgent need for ongoing screening for PTSD as well as the development and piloting of new screening and assessment tools customized to Indigenous specific historic trauma.

Adjusted rates of having a close friend or family member who had committed suicide, having self-harmed oneself on purpose, suicide ideation and suicide attempts were alarmingly high for First Nations participants in the study. Among those who had thought about suicide, a staggering 51% had made an attempt. Comparably, for on reserve First Nations, results from the 2002 RHS indicated that 30.9% reported having suicidal thoughts over their lifetime, and 15.8% reported having attempted suicide at least once in their lifetime (Assembly of First Nations, 2007b). Issues surrounding suicide have been identified as a top health problem for Aboriginal people living in cities and they continue to be inadequately addressed (Ontario Federation of Indian Friendship Centres (OFIFC) et al., 2007). We also know that the overwhelming majority of Aboriginal suicide victims also suffer from mental health disorders (Kirmayer L.J., 1994) and yet there are few agencies that offer a continuum of mental health care designed specifically for delivery to urban Aboriginal populations. It is anticipated that the data gathered through this research will corroborate and attest to the tremendous need for the sustainability and enhancement of existing services and programs aimed at Suicide prevention in urban Aboriginal settings (Anishnawbe Health Toronto, 2010; Smylie J. et al., 2011b).

In total, 55.4% of the First Nations population in Hamilton reported that they had 5 or more drinks on one occasion at least once per month, which is more than twice the rate for the general Hamilton population (26.6%) reported in the 2007 Canadian Community Health Survey (Statistics Canada, 2007a). Marijuana use was also very high with over half of the First Nations population reporting having used marijuana in the past 12 months, compared to 26.7% of RHS respondents and 14.1% of the general Canadian population who reported marijuana use over the past year (Assembly of First Nations, 2007b; Adlaf E.M., Begin P., & Sawka E., 2005). Additionally, use of cocaine, opiates and sedatives were high among First Nations individuals. Also of concern is the 17% of First Nations adults who reported having used a syringe to inject drugs and a third of those who had shared a syringe with a spouse, partner or close friend. There is growing recognition of the co-occurrence of substance misuse and mental health disorders in

non-Aboriginal and Aboriginal populations. However, there is a large knowledge and service gap for concurrent disorder treatment in this context and an even greater dearth of evidence for Aboriginal populations (O'Campo P. et al., 2009). The findings presented here are preliminary and descriptive, however drug use and associated high risk behaviours among First Nations individuals, may reflect mechanisms by which people are managing their poverty, stress and mental health issues (Smylie J. et al., 2011a). More in-depth analysis in the future will help to build our understanding of these issues including initiation into drug use, acquisition of different types of drugs, binge drug use, as well as risks and exposure to blood borne and sexually transmitted infections.

As part of the Our Health Counts survey tool, participants were asked who they had talked to in their community about an emotional or mental health problem. Aside from family and friends, very few First Nations reported having spoken with a professional or service provider, including a traditional healer. Some of this could be do to an overall lack of accessible, culturally appropriate and safe services in the community in addition to ongoing experiences with discrimination and discomfort in mainstream health care settings. When asked about barriers to receiving health care in the past 12 months, 20% reported difficulty accessing traditional care (e.g. healer, medicine person or elder) and 21% felt the service was not culturally appropriate. Compared to the results of the RHS Phase 2 (2008/10) which found that 13% of respondents had difficulty accessing traditional care and 15.4% felt that service was not culturally appropriate, urban First Nations are experiencing greater barriers to accessing health services (The First Nations Information Governance Centre, 2012).   A more detailed exploration of access to care as well as the links between experiences of discrimination and health status is beyond the scope of this paper, but will be examined in future publications. These results do tell us that despite high prevalence of psychological distress, suicide ideation and attempts and substance misuse, First Nations individuals are not communicating very much about these issues outside of their close circle of friends and family. Clearly, there are barriers that need to be explored further.

It is very important to recognize that in the face of emotional suffering, the Our Health Counts First Nations population also reported good levels of self-rated health, felt in balance of the physical, mental, emotional, and spiritual aspects of self and exhibited a strong sense of cultural identity. Resilience and concepts such as enculturation have been explored as protective

factors against substance abuse, suicide ideation and suicide attempts, and depressive symptoms in Indigenous settings (Zimmerman M.A. et al., 1996). Furthermore, our findings speak to the importance of culture-based coping mechanisms and health services for Aboriginal people.

There were some limitations with this study. Firstly, RDS cannot guarantee a random sample of network members, meaning that there may have been some room for bias with the sampling methodology. However, continuous efforts were made by the on-site study staff in order to encourage participants to distribute their coupons broadly. Furthermore, post- sampling analysis revealed that "equilibrium" had been reached – i.e. the sample had successfully distanced itself from the original sampling biases and reached a state of random selection. Another limitation with the study is that data are self-reported; therefore some variables like diagnosis of a mental health disorder may be imprecise. Participants may also under-report experiences and behaviours that are stigmatizing or too painful to recall. In order to minimize these limitations and in accordance with community-based participatory research methods, all interviews were conducted by members of the community in a safe and neutral place and interviewers provided continued assurance of confidentiality.

In conclusion, our findings clearly indicate disproportionately high prevalence of anxiety and depression, experiences of trauma, and self-harm, suicide ideation and attempts among an urban First Nations population in Hamilton. Additionally, results highlight problematic drug use and related high-risk behaviour as well as challenges linking individuals to appropriate and accessible support for these issues. Sadly, these conclusions have been voiced elsewhere and it appears that little has been done to address so many of the problems faced by urban Aboriginal people in Canada (Ontario Federation of Indian Friendship Centres (OFIFC) et al., 2007). By generating population-based health information where little previously existed and strengthening community and organizational partnerships and capacity, we anticipate that the Our Health Counts project will be a catalyst for change.

Chapter 8 Discussion

17   Summary of Results

Given limited available public health data and increasing disparities in social determinants of health for Ontario's urban Aboriginal populations, the outcomes of the Our Health Counts project filled a very important and timely knowledge gap. Through valuable partnerships and the application of a culturally appropriate community-based research framework, the OHC project produced a baseline population health database for urban Aboriginal people living in Ontario that is useful and relevant to local, regional and provincial policy makers.

The effectiveness of the OHC project is exemplified in the three nested studies presented in this thesis. The following research objectives were realized:

1. Identify current health priorities of three diverse urban Aboriginal populations in Ontario through concept mapping in order to inform unique First Nations, Inuit and Métis health assessment survey tools.

2. Recruit a representative sample of urban First Nations people living in Hamilton, Ontario using respondent driven sampling (RDS) and to generate population proportion estimates for social determinants of health.

3. Generate prevalence estimates for mental illness, substance misuse and access to emotional supports among urban First Nations adults living in Hamilton, Ontario.

In the first study, concept mapping successfully engaged over 40 urban Aboriginal community stakeholders from three communities in identifying community health concerns and priorities. After compiling statements generated during brainstorming into a master list, there were 102 unique statements from stakeholders in Hamilton, 44 statements generated by Inuit in Ottawa and 83 statements generated by Métis in Ottawa. Data from the sorting and rating of statements generated initial maps, were reviewed and finalized during map interpretation

sessions in each community. The most highly rated statements were those which focused on social determinants of health, mental health and emotional well-being. Final maps strongly reflected local First Nations, Inuit, and Métis understandings of health and contributed to three culturally relevant health assessment survey tools.

The second objective was met through the effective application of RDS, which was used to generate a representative sample of 554 First Nations adults and 236 First Nations children living in Hamilton, Ontario. Analysis of recruitment dynamics indicated that referral chains were long enough to overcome the original sampling bias. Interview data were analyzed and adjusted for RDS and revealed striking disparities in social determinants of health. In particular, 78.2% of the First Nations persons living in Hamilton earned less than $20,000 per year and 70% of the First Nations population in Hamilton lived in the lowest income quartile neighbourhoods compared to 25% of the general Hamilton population. Over 20% of the population had moved 2 times in the past five years, while 41% had moved between 3 and 5 times in the past 5 years. A total of 46% were living with more than 1-2 persons per room and 26.3% were living with more than 2 persons per room. Finally, 22% of the First Nations population in Hamilton reported that they sometimes or often did not have enough food to eat. Through the application of RDS, a sample of urban First Nations individuals who might otherwise not have participated in mainstream surveys or census was captured.

The third objective was attained through the generation of prevalence estimates for diagnosis and treatment of a psychological disorder or mental illness, depression, anxiety, post-traumatic stress disorder (PTSD), suicide, alcohol and substance misuse, and access to emotional and mental health support. Specifically, a total of 42% of First Nations people in Hamilton had been told by a health care worker that they had a psychological and/or mental health disorder and over half of these individuals this condition was limiting the kinds of activities they could do. Rates of depression and anxiety were high, 30% of First Nations people in Hamilton reported 3 or more experiences of trauma in the previous month and over 40% reported that a close friend or family member had committed suicide. Aside from family and friends, very few First Nations reported having spoken with a professional or service provider about an emotional or mental health problem. Findings clearly indicate disproportionately high prevalence of emotional suffering in the First Nations community of Hamilton.

18   Strengths, Innovations and New Contributions

The Our Health Counts project established successful partnerships between four core urban Aboriginal provincial organizations, the Centre for Research on Inner City Health, the Ministry of Health and Long Term Care, the Institute for Clinical and Evaluative Services and the communities of First Nations in Hamilton, Métis in Ottawa and Inuit in Ottawa. Balanced relationships were achieved through the project governing structure including the project Governing Council and research and data sharing agreements as well as ensuring that principles of respect, capacity building, cultural relevance, representation, and sustainability were upheld throughout the entire course of the study. In keeping with Aboriginal CBR guidelines (Fletcher C., 2003), the OHC project fostered the development of capacities within the community that contributed towards self-sufficiency and self-determination. As expressed by executive director of OFIFC, Sylvia Maracle in a press interview related to the project, "The concept of self-determination around the [OHC] data is very important. It shows us that this population wants to make a difference in their own health." (Hardy K., 2012).

Respectful and ethical CBR that upholds Aboriginal guidelines including OCAP has been gaining momentum, however there continue to be logistical and funding challenges as well as inconsistencies in levels of adherence to these principles (Schnarch B. et al., 2004; Patterson M.., Jackson R., & Edwards N., 2006; Edwards K., Lund C., & Gibson N., 2008). Furthermore, awareness and the pursuit of ethical standards and CBR principles does not always translate into inclusive or equitable research processes and data systems (Smylie J. et al., 2011b). One of the tremendous strengths of the Our Health Counts project is that community-based research was conceived, developed and implemented by Aboriginal people for the benefit of Aboriginal communities. As described above, this was partly achieved through supportive partnerships and a clear research governance model, but also through the pursuit of research methods that build on the strengths of urban Aboriginal communities. For example, the articulation and labeling of map clusters during concept mapping among First Nations in Hamilton, Inuit in Ottawa and Métis in Ottawa challenged existing illness-based narratives for these populations and served as a the platform for a traditional teaching by one of the First Nations Elders who attended the map interpretation session in Hamilton (Appendix G).

Following the completion of the OHC project in Hamilton, community and research partners organized a launch of the community report (Smylie J. et al., 2011a) at a well-attended press release in Hamilton and a website dedicated to the study was established (http://ourhealthcounts.ca/). The website not only highlights key findings from the study, it presents information about the partnerships and provides access to resources and media coverage including several you tube videos (You Tube, 2012c; You Tube, 2012b; You Tube, 2012a). A community dissemination meeting with all the relevant stakeholders provided an additional venue for feedback of results to organizational partners and allowed for collaborative strategizing around the dissemination of study outcomes into key policy and program development. The realization of these strategies has been put into effect through collaboration with the Hamilton Executive Director's Aboriginal Coalition (HEDAC) and the Social Planning and Research Council (SPRC) who presented First Nations OHC data on housing and homelessness status to the Emergency and Community Services Standing Committee of the City of Hamilton. Through this formal request, OHC results have supplemented the Department of Housing and Homelessness Report on the Evaluation and Recommendations of the Homelessness Partnering Strategy (City of Hamilton, 2011).

Given the near absence of population health information for urban Aboriginal people in Canada, this research is able to provide, for the first time, First Nations health data that clearly demonstrate alarming inequities in areas such as housing, income and mental health disorders. This newly established health database represents a significant contribution to public health that will directly inform strategic directions for the improvement of health and social status of urban Aboriginal people in Ontario.

19   Limitations

The concept mapping in each study site involved qualitative purposive sampling, which generated relatively small sample sizes. Thus, study populations may not have been representative of all the community health organizations and stakeholders among First Nations people in Hamilton, Inuit in Ottawa and Ottawa Métis populations. Concept mapping in three urban Aboriginal settings with a broad range of participant characteristics presented some challenges, particularly around the interpretation of a more 'crowded' map in the Ottawa Métis population. Currently, concept mapping processes are limited in capturing community

characteristics like the cultural diversity and dispersion of Métis people living in Ottawa. As highlighted by a recent pooled analysis of 69 concept mapping studies, there are several areas of concept mapping inquiry which are currently incomplete such as content analysis in areas where multiple concept maps have been produced and a need for more investigation around the impact of participant dynamics on concept mapping procedures (Scott R.R. & Kane M., 2012).

As described in the second paper, one main limitation with RDS is that it cannot guarantee a random sample of network members; therefore, there may have been some room for bias with the sampling methodology. It should also be noted, that we may have under sampled the elderly First Nations population living in nursing homes and other institutions in Hamilton. During our initial seed selection, we did not select any seeds from this population, which may have resulted in an under representation of First Nations individuals over 65 years of age. An additional limitation with RDS is that at present, RDS methodology has not developed weights for multivariate analyses. Through a systematic review of HIV biological and/or behavioral surveillance studies using RDS in published and grey literature, Johnston et al. concluded that there is no consensus on the appropriate statistical methods for using RDS in more complex analyses such as multivariate linear or logistic regressions (Johnston L.G., Malekinejad M., Kendall C., Iuppa I.M., & Rutherford G.W., 2008). The prevalence estimates generated for the Our Health Counts and the adjusted linkage between study participants and ICES data greatly contribute to a current deficit in available population health data for urban First Nations people in Ontario. However, given this limitation with RDS, we are unable to explore and measure more complex associations between outcomes.

It is very important to recognize that levels of high mobility, overcrowding and low income reported by First Nations in Hamilton is likely associated with an under-reporting of socio-economic stressors and ill health. This must be considered when interpreting the results of self-report questions such as self-rated mental health (i.e. 64% of First Nations adults reported excellent or good mental health). There are several explanations for under-reporting which need to be taken into consideration. Firstly, there may be some stigma around self-reporting of one's financial situation and meeting basic needs (i.e. not having enough food to eat). Secondly, individuals in a population that has experienced longstanding adverse conditions may have internalized notions of "not being good enough" and therefore accept what others might perceive

as hardship or may lower their expectations when faced with such chronic hardships (Maar M.A. et al., 2011; Absolon K.E., 2010)(Urban Aboriginal Youth Report 2003).

At the same time, the income data generated through the OHC study may be considered a more representative income profile of the First Nations population in Hamilton compared to the 2006 Census. Namely, the OHC data were validated and adjusted for bias using RDS statistics and captured more 'hidden' populations such as persons who are homeless, transient or who have low literacy skills, which are known to be under-represented in the Census (Smylie and Anderson 2006; Anderson and Smylie 2009) and were all issues with high prevalence in the First Nations population in Hamilton. Further validation of the OHC survey income data is highlighted by the RDS adjusted ICES income quintile data (reported in paper 2), which revealed that over 70% of the OHC cohort was in the lowest income quartile compared to 25% of the general Hamilton population and 20% of the Ontario population. Comparisons between the OHC cohort and the Census must be made with caution however, due to differences in the terms for defining Aboriginal identity. Specifically, the Canadian Census asks individuals to indicate if they have Aboriginal ancestry and then to identify as North American Indian, Métis or Inuit (Census Canada Analysis Series 2001), whereas for the OHC study, participants who self-identified as both Status (Registered Indian according to the Indian Act) and non-status First Nations, could then identify their Nation as well as reserve or band affiliation (see Appendix C).

20 Implications for Future Research

The study outcomes presented here clearly highlight the importance and need for more government funds and resources to support collaborative, participatory-action research efforts with urban Aboriginal communities and organizations. Related, the partnerships formed and strengthened through this research are critical to addressing and resolving health disparities for urban Aboriginal people. Thus, municipal, provincial and federal governments need to support interagency collaboration and multi-sector cooperation among Aboriginal organizations, service providers and researchers in the design and delivery of services (Smylie J. et al., 2011a). Moreover, such support must be inclusive of a recognition and understanding of the terms of OCAP and urban Aboriginal communities' rights to self-determination and governance of research and health services, programs and delivery. Given that the majority of public health

funding, policy and program development supports Western methods and models, initiatives that are rooted in Aboriginal knowledge systems and are controlled by Aboriginal people are greatly under funded (Tait C.L., 2008). There are initiatives (Assembly of First Nations, 2007a; Kahnawake School Diabetes Prevention Program, 1996) like the Our Health Counts project that are emerging to address this imbalance. The urban Aboriginal population in Canada is growing and has unique health needs and social determinants of health which must be addressed in policy and programming (Adelson N., 2005; Wilson K. & Cardwell N., 2012).

The findings from the OHC study raised some questions about urban Aboriginal health that require further investigation. In particular, high prevalence of mental health disorders as well as elevated marijuana and opiate use and reported injection drug use among First Nations adults in Hamilton is of tremendous concern (communication with Constance McKnight ED De dwa da dehs ney>s Aboriginal Health Access Centre). More research is needed to understand the extent, characteristics and context of concurrent mental health and substance use disorders as well as the prevalence of non-medical use of prescription opioids and associated morbidity and mortality risks among urban First Nations. Furthermore, while this baseline evidence indicates high prevalence of emotional suffering and unmet basic needs, understanding community survival, resilience and strengths-based coping mechanisms in the face of these challenges is an important future direction for research. Finally, the success of RDS in Hamilton has also led to the planning of a Greater Toronto Area (GTA)-based RDS study on urban Aboriginal family health through a partnership between St. Michael's Hospital, the Toronto Local Health Integration Network (LHIN) and other local Aboriginal health services.

21 Conclusions

This original research not only contributes to a deficit in accessible and culturally relevant population health data for urban Aboriginal people, it also 'walked the talk' of community-based research. In order to truly reduce health and social inequities, we need to transform health and social research tools, data systems and governance from those which perpetuate social exclusion and marginalization to those which support true community empowerment (Smylie J. et al., 2011b). The Our Health Counts project, from inception to ongoing knowledge translation is contributing to this transformation in Indigenous health research.

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Appendices

Appendix A: Research Agreement (Ontario Federation of Indian Friendship Centres (OFIFC), De dwa da dehs ney>s Aboriginal Health Access Centre (DHAC), St. Michael's Hospital (SMH))

Appendix B: Research Agreement (Tungasuvvingat Inuit (TI), St. Michael's Hospital (SMH))

Appendix C: Research Agreement (Métis Nation of Ontario (MNO), St. Michael's Hospital (SMH))

Appendix D: ICES Data Sharing Agreement

Appendix E. Concept Mapping Statements

Appendix F: First Nations Adult Survey

Appendix G: First Nations Concept Map – Superimposed Medicine Wheel