Our Health Counts: Access to health risk factors and its relationship to diabetes in an urban First Nations population.

Michael Beckett

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Abstract

This thesis explores the relationship between health access risk factors and diabetes in an urban First Nations population living in Canada. The proportion of Aboriginal peoples in Canada living in urban areas is increasing. Despite this, health data on urban Aboriginal populations in Canada is sparse and often unreliable. The Our Health Counts (OHC) study collected data from a self-identified urban First Nations population living in Hamilton, ON through respondent driven sampling. As statistical techniques for this data are not yet fully developed, advanced logistic regression modeling strategies were used to assess the relationship between health access risk factors and diabetes. Feeling health services were not culturally appropriate was significantly associated with an increased odds for diabetes (12.07, 95% 2.52, 57.91). A strong potential effect between diabetes was also found for the following barriers: not being able to locate a doctor in the area; feeling health care services accessed were inadequate and if health services were not being offered in the area. Furthermore, this study examined the sensitivity of results for various analysis strategies for data that were obtained using respondent driven sampling (RDS). This study could allow for the implementation of more targeted health interventions and the design of health policies that are more specific to target the urban First Nations population in Canada, as well as provide insight into the use of appropriate statistical methods for data collected through respondent driven sampling.

Keywords: First Nations, Diabetes, Health Access

ACKNOWLEDGEMENTS

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List of Abbreviations

Term	Abbreviation
Our Health Counts	OHC
Respondent Driven Sampling	RDS
Aboriginal Peoples Survey	APS
Canadian Community Health Survey	CCHS
Urban Aboriginal Health Centres	UAHC
Body Mass Index	BMI
First Nations and Inuit Regional Health Survey	FNIRHS
Socioeconomic status	SES
Generalized Linear Model	GLM
Generalized Linear Mixed Model	GLMM
[AR(1)]	First order auto-regressive correlation structure
[ARMA(1,1)]	First order autoregressive moving average correlation structure
Odds Ratio	OR
Confidence Interval	CI
Non-insured health benefits	NIHB
Institute for Clinical Evaluative Sciences	ICES

INTRODUCTION

Significant health inequalities between the Aboriginal population and the non-Aboriginal population in Canada are becoming increasingly commonplace (1). Aboriginal populations in Canada suffer from a disproportionate number of health disparities, including an abnormally high prevalence of hypertension, diabetes and cardiovascular diseases (2). The prevalence of diabetes is three times higher among Aboriginal peoples in Canada, compared with non Aboriginal peoples (3) and cardiovascular diseases are the most common cause of death for urban Aboriginal men and women aged 25 years or older (4), despite their recent decline among the non Aboriginal population (5). These health disparities may be reflective of underlying social, cultural and political inequities within the Aboriginal population living in Canada (5). Research on Aboriginal peoples has shown that the majority of the inequities faced by this population can be traced back to the discrimination and violation this group of peoples endured during European colonization (5). The inequities experienced by Aboriginal peoples in Canada are further complicated by the growing urbanization of this population. As First Nations peoples move off reserves towards more urban centres they face new barriers when accessing health care (6). Furthermore, census data on the Aboriginal peoples in Canada is sparse and often unreliable (6, 7). The lack of comprehensive health data on this growing urban population hinders the implementation of substantial policy changes targeting urban Aboriginal peoples, or for possible health determinants for this population to be explored in greater detail (6, 7).

Given the growing number of urbanized Aboriginal peoples in Canada, and the lack of health data on this population, the primary objective of this study is to use various

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modified logistic regression modeling techniques to examine the relationship between the prevalence of diabetes and health access risk factors of interest for First Nations peoples living in the city of Hamilton, Ontario. Specifically, these models will explore known access risk factors for diabetes, including barriers to accessing to health services, inadequate nutrition, a high mobility rate and socioeconomic factors. The barriers to accessing health services will include a list of twelve potential barriers an Aboriginal person could incur when accessing health services, including the unavailability of doctors, lack of affordability of services or an overall lack of trust in health care providers. Confounders that will be controlled for include age, sex, physical activity level, body mass index (BMI), smoking status and alcohol consumption. These research questions are of primary interest to our Aboriginal community partners who have informed the direction and scope of this project to maximize benefit to the Aboriginal community.

Data

All data for this study were collected from the Our Health Counts urban First Nations peoples health study, in partnership with the De dwa da dehs ney >s Aboriginal Health Access Centre in Hamilton. Data were collected from 554 self-identified First Nations adults and 236 children, from December 2009 to April 2010. All data was collected through respondent driven sampling (RDS) techniques.

Methodology

Respondent driven sampling was used to collect health information from the urban First Nations population living in the city of Hamilton. Standard statistical

regression models have not yet been developed or validated for this advanced statistical sampling technique, thus we examined the use of two competing approaches, both of which have a sound statistical basis.

RDS is traditionally used to collect data from hidden or marginalized populations that cannot be reached using traditional sampling techniques (8). Traditional approaches to study these hidden populations, such as convenience and snowball sampling, are prone to various forms of bias (8), as they are sensitive to the choice of locations and choice of initial participants (8). RDS limits this selection bias. As the recruitment chains grow longer, eventually a sample composition that is representative of the target population, independent of the selection of initial study members, can be achieved (9). Furthermore, unlike traditional snowball sampling, RDS can provide asymptotically unbiased estimates provided the recruitment chains are of sufficient length (9).

A primary objective of this study is to use the proposed, modified multivariable logistic regression modeling approaches and to examine the relationship between diabetes and health access risk factors of interest. However, methodological challenges arise in the ability to appropriately account for unequal sampling probabilities that exist in the RDS sampling framework, as some individuals with larger network sizes are more likely to be recruited into the study than others. Moreover, correlation between responses needs to be accounted for, as individuals tend to recruit people who are like themselves. To account for these considerations, a generalized linear mixed model and survey-based analysis approaches will be used for the logistic regression of the RDS data.

This proposed study could allow for the implementation of more targeted health interventions and the design of health policies that address specific health access issues that are affecting the metabolic health of urban First Nations populations in Canada. Despite the growing urban First Nations population in Canada, health research on this population remains underdeveloped and health disparities continue to exist for First Nations populations, especially in urban environments. Learning how health access variables interact to affect the diagnosis of diabetes of urban First Nations populations could assist with policy making to ensure that First Nations individuals are receiving the necessary care to thrive in all their living environments. Moreover, the development of more appropriate statistical methods for RDS studies could support the design of future research projects that target marginalized populations.

Chapter 2: Literature Review

2.1 Overview of Aboriginal peoples living in Canada

The indigenous peoples of Canada include people of First Nations, Inuit and Métis descent (10). The term Aboriginal, introduced in the Constitution Act of 1982, includes all individuals living in Canada who self-identify as either Indian, Métis or Inuit, regardless of whether they live on or off a reserve or whether they have status granted from the Indian Act (11). First Nations peoples refer to Status and non-status Indian peoples in Canada and many communities in Canada use the term First Nations in their name (12). In this report, the term Aboriginal peoples will be used to refer to the diverse groups of indigenous peoples in Canada, including those who self-identify as either First Nations, Métis and Inuit peoples, unless otherwise specified as per the request of our Aboriginal community partners.

Aboriginal health assessment data is sparse and unrepresentative of the Aboriginal population in Canada (13). Health data on the Aboriginal peoples of Canada can be derived from the Census of Canada and the Aboriginal Peoples Survey (APS). The APS is a national survey of Inuit peoples, Métis peoples and First Nations peoples living off reserves, in either rural or urban locations (14). The APS collects data on education, employment, and health status and was administered by Statistics Canada in 1991, 2001, 2006 and 2012 (15). National level data on Aboriginal peoples living in Canada can also be obtained through the Canadian Community Health Survey (CCHS), although this survey was not designed to target these populations and does not include First Nations peoples living on reserves (16). The comprehensiveness of the health data collected on

Aboriginal peoples living in Canada is further complicated by the fact that the definition of Aboriginal ancestry differs in the Aboriginal Peoples Survey, the Canadian Community Health Survey and in census data collected by Statistics Canada (15). Census data on the Aboriginal population in Canada is limited in that coverage of First Nations peoples on and off reserves is incomplete and under-representative of that population (7). According to a 2011 National Household survey, approximately 1.4 million people living in Canada self-identified as Aboriginal, corresponding to about 4.3% of the total Canadian population; up from 3.8% in 2006 (17). Of those who completed the 2011 National Household Survey, 60.8% self-identified as a First Nations person, 32.3% identified as Métis only and 4.2% identified as Inuit only. The results from this survey also indicated the Aboriginal population is younger than the general Canadian population (17).

2.2 The urbanization of First Nations peoples in Canada

Throughout the last few decades, there has been a strong trend of First Nations peoples moving from reserves towards more urban centres. Statistics Canada (2007) defines an urban area as an area with a population of at least 1,000, or 400 persons per square kilometer (15). According to the 1951 Census, 7% of self-identified Aboriginal peoples living in Canada lived in urban areas (6). By 2001, this number had increased to 49% (6) and to 54% by 2006 (16). According to 2008 Statistics Canada, of the self-identified First Nations peoples who indicated that they lived off reserve, 76% lived in an urban area (11). The Canadian city with the current largest urban Aboriginal population is Winnipeg (18). For the majority of non-Aboriginal peoples in Canada, the transition from rural to urban areas largely occurred between 1921 and 1931 (19). For the First Nations

peoples living in Canada, the transition to more urban centers did not start until the 1950's (19). Decisions to move to urban centers are influenced by the possibility of more economic and social opportunities located in urban centres, as well as more opportunities to obtain stronger educational and career training (18). Aboriginal peoples who migrated to major cities were usually not wanted and faced strong discrimination from the non-Aboriginal residents living there (4, 6). The earliest studies on the urbanization of Aboriginal peoples living in Canada began in the 1970's and credited the problems Aboriginal peoples were having to thriving in an urban setting, to issues with substance abuse, theft and poverty, rather than issues of marginalization and discrimination (6). Research has indicated that First Nations peoples moving to urban areas from reserves face immense challenges in establishing their culture and community in these new urban areas (11). The migration of Aboriginal peoples to more urban areas is unique to this ethnic group and cannot be compared with the issues faced by other migrant groups, as many cities were established on lands that were historically used by the Aboriginal peoples (11,15). Aboriginal peoples that move to urban areas are still moving within land that was traditionally theirs, before they were forcibly displaced, and therefore the discrimination they incur in urban spaces cannot be directly compared to that of other migrants.

Given the increasing numbers of First Nations peoples in urban centers, it might seem straightforward to conclude that the increasing presence of First Nations peoples in urban centers is the end result of mass emigrations from rural reserves, however this is not the case. In fact, research on the net migration of the Aboriginal peoples in Canada reveals that more First Nations individuals actually moved to reserves, from urban

centers, between 1996 and 2006 (20). Part of the observed increase in the population of

urbanized Aboriginal peoples in Canada might be attributable to an increase in ethnic

mobility amongst this population (20). Ethnic mobility occurs when an individual or a

family changes how they report their ethnic identity in a census over time (21).

Comparing the 1996 and the 2006 census 59,000 more individuals self-identified as a

First Nations person living off reserve in 2006, compared to 1996 (20). The accelerated

growth in urban centers could also be attributable to higher birth rates of Aboriginal

peoples in Canada (20). Between 1996 and 2001, the fertility rate for First Nations

women was 2.9 children and for Métis women was 2.2, both of which are higher than the

rate of 1.5 children among non First Nations women in Canada (22). In the United States,

research has shown ethnic mobility to be a significant contributor to the growth of the

American Indian population living in urban cities (23). Improvements in the perception

of Aboriginal peoples by society are thought to increase the likelihood that Aboriginal

individuals will formally identify as such on a census form. Furthermore, major

legislative changes, such as the implementation of Bill C-31, which made changes to the

Indian Act, reinstating First Nations status for those individuals who lost it, could be

another contributing factor to the recent increase in self-identified First Nations

individuals living in urban areas (11).

2.3 A history of health inequities endured by Aboriginal peoples in Canada

       A history of colonization and subsequent paternalism by the Canadian

government, including the creation of the reserves systems and the removal of Aboriginal

children from their families into residential schools, have all contributed to many of the

health disparities plaguing Aboriginal populations living in Canada today (1, 6, 24).

Since the arrival of the Europeans, the Aboriginal peoples of Canada have been marginalized and placed at a point of social, economic and political disadvantage. Through forced colonization, the Aboriginal peoples not only lost their land, but their right to freely practice their culture, all of which had a dramatic effect on their notion of self-worth (1,6). Research suggests that the harsh effect of colonization and discrimination the Aboriginal peoples faced in the past, currently manifests itself with higher rates of suicide, injury, substance abuse and poor health outcomes disproportionately suffered by Aboriginal peoples living in Canada (1). Research has shown that placement in residential schools in particular, where Aboriginal children were forcibly removed from the their families and emotionally and physically abused, have taken a particularly detrimental toll on the overall health of Aboriginal peoples in Canada, and these past traumas are still manifesting themselves today within this population (18).

Shah and Farkas (25) published one of the earliest reports on the health disparities plaguing First Nations peoples who migrated to urban centers from rural reserves in Canada. The researchers cited discrimination, low socioeconomic status and substantial cultural differences as some of the primary reasons for these health disparities and the inability of First Nations peoples living in urban settings to acquire adequate health care. Aboriginal peoples are unfamiliar with the health care system in urban settings, as it differs greatly from the community-based health systems on the rural reserves they are accustomed to (25). Shah and Farkas (25) indicated that the health care usage of First Nations peoples in urban centers was often inadequate or inappropriate, as First Nations peoples were forced to seek non-emergent care from the emergency rooms of hospitals

because they did not have access to a family physician. A profile of First Nations peoples living in British Columbia showed that the rate of admissions to hospitals was four times higher for urban First Nations peoples, than that of the urban non-First Nations population (25). A lack of health insurance was also cited as a significant barrier that prevented urban First Nations peoples from accessing appropriate primary care services (25). Traditionally the Federal government has held the responsibility for the health needs of First Nations peoples living on reserves, but as more individuals move to urban centers, the governmental body in charge of their care remains uncertain.   The authors of this report conclude by also highlighting the jurisdictional discrepancies that are also contributing to a lack of adequate health care needs for urban First Nations peoples. Furthermore, the authors cited a need to establish a stronger sampling frame in an urban setting to explore health barriers among urban First Nations peoples, and the dire need for more culturally sensitive care to be made available to this growing urban population (19).

Another early report by Waldram (26) examined the movement of First Nations peoples from reserves to urban areas. Waldram (26) acknowledged how resilient the First Nations peoples living in Canada are, as evident by their ability to preserve their core cultural practices and values on both reserves and in urban centers, despite enduring a history of extensive discrimination and oppression from both the Canadian and American governments. Waldram (26) commented on the migration of First Nations peoples from rural to urban centers, citing that the move off reserves was motivated primarily by a desire to achieve greater economic and social success in cities, and not necessarily to adopt a Western culture lifestyle. Waldram (26) acknowledged how little research has been done to examine how First Nations peoples have adopted their traditional health

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beliefs into a more urban setting. In his paper, he strives to identify what the term health care access truly encompasses; remarking that a delay in receiving treatment, poor communication to service users and an overall expensive cost of service are all factors that should be considered; as well as social factors relating to the group seeking the service. In an interview with 142 First Nations people living in the city of Saskatoon, 60% of respondents indicated they would like their first point of contact with the medical system to be with an Aboriginal traditional healer, regardless of how long they had lived in the city (26). Ultimately, it was preferred if traditional aspects of Aboriginal medicine were utilized in conjunction with modern western medical practices. Through his research, Waldram (26) was able to demonstrate that First Nations peoples living in an urban setting still possess a strong desire to use traditional medicine, and significant improvements in access to medical services is needed.

Benoit et al. (27) sought to investigate how the needs of Aboriginal women were being met with the implementation of Urban Aboriginal Health Centers (UAHCs). Literature that existed prior to this report indicated that Aboriginal women lack adequate medical services, access to reproductive care services and access to adequate illness prevention centers (27). UAHCs were implemented to improve the health status for Aboriginal peoples in Canada by increasing access to more culturally appropriate services in urban areas. Through the use of semi-structured interviews, participant observation and focus groups, Benoit et al. (27) recorded individual perceptions of health care access from female Aboriginal respondents at various downtown Vancouver clinics. Three focus groups, each comprised of 12 self-identified Aboriginal women, were conducted to gain different perspectives on the effectiveness of health care access for

Aboriginal women living in Vancouver's downtown east side. Overall, the women interviewed sought out medical staff that were sympathetic to the racism and sexism they constantly tolerate and the toll it has on their overall health and feelings of self-respect. The inability to locate child-care services was another issue that prevented these women from accessing adequate medical care (27). The majority of the women interviewed still sought out more culturally appropriate health services, indicating that their health needs were still only being partly met with the implementation of the UAHCs. The authors of this paper noted that the women interviewed displayed an incredible inner strength and resilience when sharing their experiences. Aboriginal women who migrate to the city usually find themselves feeling isolated and without a strong cultural base to access when they are in crisis. The authors of the paper suggest the government adopt policies from experienced Aboriginal women living in urban areas to create new innovative health policies that reduce the discrimination and lessen the challenges these women endure on a daily basis. The findings of this report are limited in that the sample of respondents recruited into the study was non-random, small and comprised entirely of women, so a generalization for the entire urban Aboriginal population living in Canada cannot be made. Furthermore this data focused exclusively on self-identified Aboriginal women living in the downtown east side, excluding Aboriginal women who lived in the other neighborhoods of Vancouver, or perhaps were not accessing services provided by the UAHC. This report however does shed some important light on the issue of modern health care access for Aboriginal women living in urban centers.

Tjepkema (28) produced one of the first reports to compare the health status and health care utilization of off reserve First Nations and Aboriginal populations, with their

non-Aboriginal counterparts, while adjusting for different health socio demographic variables. In his analysis, using data from self-identified Aboriginal persons on the 2000/2001 Canadian Community Health Survey (CCHS), he found that after adjusting for age, income and geographic location, 23% of self-identified Aboriginal peoples and off-reserve First Nations peoples rated their health as either poor or fair, which is 1.9 times higher than the non-Aboriginal respondents. Furthermore, 60% of the off reserve First Nations and Aboriginal population reported at least one chronic health condition, which differs significantly compared to only 49% of the non Aboriginal population. Diabetes was listed as one of the top chronic conditions affecting the off reserve First Nations and Aboriginal community and the prevalence of diabetes was significantly higher for urban Aboriginal peoples compared with their non-Aboriginal urban counterparts. Furthermore, 19.6% of the off reserve First Nations and Aboriginal respondents cited having at least one un-met health need, which was statistically significantly higher than 13% for the non Aboriginal population (28). A lack of accessibility and service availability were cited as the main reasons for having an unmet health need. A series of multiple logistic regression models, adjusted for different socio-economic and health behavior variables, were examined for different health outcomes. After adjusting for socioeconomic variables, including educational status, income and work status, as well as health behaviors, including physical activity, smoking habits, drinking habits and BMI, urban Aboriginal peoples had significantly greater odds in reporting at least one chronic condition in the previous year, reporting a health status of only fair or poor or a greater likelihood of reporting a major depressive episode in the previous year, compared to their urban non Aboriginal counterparts (28). The CCHS also

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allows for an analysis on health care utilization. In 2000/2001, 76.8% of the self-identified off reserve First Nations and Aboriginal population reported seeing a physician in the previous year, which was not significantly different from the non-Aboriginal urban population. However, urban Aboriginal individuals were significantly less likely to have had contact with a dentist in the previous year. This could be because dentists are not publicly funded, making cost a prohibitive barrier in this case (28).

Limitations of this study by Tjepkema (28) include the possible presence of recall bias, as well as possible discrepancies in how self-identified Aboriginal individuals may respond to sensitive questions about their personal health, particularly because data for the CCHS is collected through personal or telephone interviews, unlike census data which uses self completed questionnaires (28). As well, studies have shown that cultural minorities interpret questions differently and waiver in their willingness to disclose sensitive information (28). Furthermore, Aboriginal individuals may be hesitant to disclose their culture or race on nation wide surveys, so it is likely the off reserve Aboriginal community is underrepresented in this survey. Self identified off reserve First Nations and Aboriginal peoples, especially those living in an urban setting, are more likely to live in households with 5 or more people, and because household size was used to determine income level, the total number of low income Aboriginal households may have been underestimated. Finally, because data from the CCHS is cross-sectional, no causal relationships between any of the variables could be inferred. The definition of off reserve for self-identified Aboriginal individuals includes individuals that live in both a rural and urban setting. A similar trend in health disparities was found between both the rural and urban off reserve populations, although no follow up statistical tests to look for

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any significant differences between the two groups were performed. A strength of this study was the adjustment for age, given that the off reserve Aboriginal population in Canada tends to be younger than the non First Nations Canadian population.

In a follow up study by Tjepkema et al. (4), the authors analyzed data from the 1991-2001 Canadian census mortality follow up study to compare the mortality patterns for urban Aboriginal adults, with urban non-Aboriginal adults. It was one of the first in-depth studies to examine the mortality patterns for a large number of urban Aboriginal peoples. Compared to urban non-Aboriginal peoples, the life expectancy for urban Aboriginal peoples was 4.7 years shorter for men and 6.5 years shorter for women. Circulatory diseases were the most common cause of death among urban Aboriginal men and women. In their paper, the authors acknowledge the difficulty in tracking the causes of death for urban Aboriginal peoples, as ethnic identifiers are not always reported with death registrations. Furthermore, respondents were identified as urban, based on where they were living at baseline, on June 4 1991. Given the transient nature of the urban Aboriginal population, it is possible individuals moved during the follow-up period. Moreover, all socioeconomic and health variables used in the analysis were collected at baseline, and could have changed during the follow up period. One of the strengths of this study was the use of the 1991-2001 census mortality data, which allowed for data to be analyzed from urban Aboriginal groups from all provinces, regardless of whether the respondents were formally registered as status First Nations under the Indian Act. However to be considered eligible, an individual must have been enumerated by the 1991 census long-form questionnaire, at least 25 years old at the time of the census and have filed a tax return for the previous year. The 1991 census missed 3.4% of all Canadian

residents, and those excluded from the census were likely to be younger, homeless or of Aboriginal ancestry, thus data used in this study may not be truly representative of their target population (4).

In a Medline search of journal articles published between 1992 and 2001, Young (29) determined that not enough research articles detailed the health of Canada's Aboriginal peoples, particularly Métis peoples, Aboriginal peoples living in an urban environment and First Nations peoples living off reserves. Socioeconomic and cultural barriers have not been examined in great detail. Research papers that have studied the health of urban Aboriginal populations have usually only come from a select number of geographic regions within Canada, such as Vancouver or Winnipeg. A significant gap in health research on this topic still exists. One of the more recent studies to examine health disparities of the urban Aboriginal population living in Canada was reported by Senese et al. (24). The authors interviewed 36 individuals who self identified as Aboriginal and had recently moved from a rural area or reserve to the city of Toronto. Interviews took place between February and March 2011. Demographically the study consisted of 78% women, and 21 of the participants had lived in the city for at least five years (24). Expressing their cultures in an urban space was very important to the participants. When asked to elaborate on their experience of Aboriginal rights in the city, many of the participants related rights with access to health services and forms of respect for Aboriginal cultures and identities. Many of the interviewees expressed significant frustrations when attempting to access health services and benefits in the city. Ten of the participants felt it was a constant struggle to access health services and benefits in the city and twenty-four of the participants felt their access to Aboriginal rights based services and benefits, was

limited in the city compared to on the reserve. Participants also described feeling

discriminated against by health care providers when they tried to pay for their services

using their non insured health benefits for First Nations, and how they were sometimes

turned away after providing their Aboriginal documentation. The daily discrimination

they incurred because of their ethnicity also prevented them from regularly using their

status cards, which entitles them to receive financial benefits. Not only does this kind of

discrimination prevent them from accessing the care they need, but disrespects their

identify and cultural heritage, which can be detrimental to their overall health (24). Given

the small study sample of interviewees, comprised mainly of women, the perspectives

gained from this study are not generalizable to the entire urban Aboriginal population in

Canada. However this study does provide some unique and detailed insight into the

health access barriers modern day urban Aboriginal peoples living in Canada are

incurring and the constant struggle to be respected as an Aboriginal person in an urban

place. Based on the limited literature, this thesis will provide additional insight into

impact of access to health services and their association with diabetes in an urban

Aboriginal population.

2.4 The concept of Access to Health Care Services

The responsiveness of health services can be measured in accordance with their

standards of availability, accessibility and acceptability (30). Health literature continues

to show that certain marginalized groups are more vulnerable to becoming ill, yet are less

likely to seek out appropriate care (18). Examples of marginalized groups in Canada

include people with mental illness, people with substance abuse problems and the

Aboriginal population living in Canada (18). Access to primary care centres in urban

areas should be a substantial concern as the number of Aboriginal peoples living in urban areas continues to rise (18). Population level data from Canada has shown that First Nations peoples in urban areas utilize fewer community based health support programs, and have higher rates of non-emergent admission to hospital emergency rooms (18). In British Columbia, the age standardized mortality rate for treatable diseases is between 2 to 5 times higher for First Nations peoples in Canada, compared to their non First Nations counterparts (18). In 2006 the life expectancy for urban First Nations peoples living in Winnipeg was 10.2 years less than non-Aboriginal peoples in Canada for women and 9.6 years less for men (18). These differences in health can be attributed to social and cultural determinants, as well as reflective of significant gaps in access to primary care services (18). One indicator of a lack of access to primary care services can be the misuse of hospital emergency rooms, for non-emergent problems. Research has indicated that individuals who feel marginalized, uncomfortable with community based health services or who do not have access to a primary care provider, are more likely to seek help at emergency rooms for non-emergent care (18). To explore the perspectives on access to primary care, researchers recruited respondents who were utilizing the non-urgent division of the emergency room of an urban teaching hospital in the city of Vancouver. Using individual, in-depth interviews, over a 20-month period, data was collected from 44 participants, 34 of whom self-identified as Aboriginal. Participants were asked about their experience accessing health services in the city. Overall themes from the interviews was a general concern over their inability to receive adequate medical care given their ethnic background, perceived boundaries that prohibited them from accessing health services in more upscale neighborhoods and the inability to receive adequate treatment

for chronic pain or illnesses that could otherwise be managed with access to primary care

pain management therapies (18). Some of the respondents felt discriminated by hospital

staff, primarily due to their Aboriginal heritage and went as far to say they felt the

hospital staff regarded them as drug users and addicts (18). Frustrations from hospital

staff over a respondent's inability to seek care outside of the emergency room do not take

into consideration the likely plausibility that for some of the respondents, growing up in a

government mandated residential school has established a feeling of dread and

anxiousness when addressing authority figures, including health care providers (18).

Research on Aboriginal groups in Canada, New Zealand and the U.S. continue to show

that the effects of colonization continue to impact access to care for many First Nations

groups (31). The harsh effects of colonization have fostered a deep distrust in many

government agencies, making the utilization of mainstream health services

psychologically stressful for many First Nations peoples (31). The main themes that

emerged from the interviews collected by Browne et al. (18) provide further insight into

the experience of health access for urban Aboriginal populations and the socio-cultural

barriers that prevent many Aboriginal populations from accessing care in a timely and

efficient manner.

Access II: The issue of government policy

Despite a greater proportion of First Nations peoples in Canada living in urban

centers than on reserves, public health policy tends to put a greater emphasis on the First

Nations populations living on reserves (3). This is problematic, as urban populations face

different health access barriers than rural populations. Urban Aboriginal peoples are

concentrated in major cities and a lack of specific government policy for this group is

contributing to the emergence of substantial inequities within this group (3). The

Canadian provincial and federal governments have been hesitant to create policies that

are specific for urban Aboriginal peoples, due to disagreements over responsibility and

designation of legislative branches that would be responsible for the health of this group

(3). The Constitution clearly designates responsibility of First Nations peoples living on

reserves to the federal government, while governance over the urban First Nations

community is still up for debate. The provinces have historically responded by ensuring

that all Aboriginal peoples are the primary responsibility of the federal government (3).

Stronger co-ordination between provincial and federal governments is needed to create

any remarkable change for the urban Aboriginal community. The Royal Commission on

Aboriginal peoples report (1996) outlined that the First Nations population living in

urban areas do not receive the same benefits as their counterparts that live on reserves,

and incur significant barriers when trying to access provincial programs located in urban

centers (3, 24). Federal-provincial jurisdictional disputes, substantial cultural barriers and

recurrent discrimination are all contributing factors that have contributed to hindering

health access for the First Nations population living in Canada (32).

2.5 Diabetes in the Aboriginal Population living in Canada

Diabetes is becoming a serious health concern among the Aboriginal population

living in Canada. Research suggests the prevalence of diabetes is three to five times

higher among Aboriginal peoples compared to non-Aboriginal peoples in Canada (33). In

2010, the Heart and Stroke foundation of Canada reported that the Aboriginal population

in Canada was experiencing a cardiovascular disease crisis, citing endemic levels of

diabetes, hypertension and heart disease (34). Young et al. (35) analyzed data from the

1991 Aboriginal People Survey (APS) and the 1997 First Nations and Inuit Regional

Health Survey (FNIRHS). According to the FNIRHS, after adjusting for age, the

prevalence of diabetes among First Nations peoples was 3.6 and 5.3 times higher for men

and women, respectively. It should be noted that data from the FNIRHS comes from self

identified First Nations living on reserves from all provinces in Canada. Data from this

study also showed that First Nations individuals with diabetes suffered a high rate of co-

morbidities. In their paper, Johnson et al. (33) sought to explore the difference in the

prevalence of diabetes between urban and rural First Nations peoples living in Alberta.

Accessing the Alberta Health and Wellness administrative data, Johnson et al. (33)

collected health data on the hospitalizations, physician services use and emergency room

visits for all eligible residents of Alberta. First Nations individuals were identified if they

were formally registered under the Indian act and had status. The authors found that

between 1995 to 2006, after adjusting for age and sex, the prevalence of diabetes

increased 22% among status First Nations peoples in urban residences and 35% for those

in rural locations. The prevalence of diabetes was higher among First Nations women,

regardless of location. This could in part be due to the presence of gestational diabetes,

which may not have been coded differently from diabetes and subsequently included in

the analysis. However these results are limited, as only those First Nations people with

status who are formally registered under the Indian Act were accounted for, neglecting

anyone who may self identify as Métis, First Nations or Inuit, but are not registered under

the Indian act. Furthermore, for their analysis, classification as either rural or urban was

based on postal code for home address with their registered health data. This is another

limitation however, as there has been shown to be a high rate of migration for First

Nations peoples between urban and rural settings and no updates on addresses were made during the 10 year follow up period for any participants (33). The authors of this paper were not able to explore how regular health access or socio-economic variables may influence diabetes outcomes in this population. In an analysis on the association between First Nations status, education and income in the city of Winnipeg, the authors used data from the 1996 Census Canada to see how a self-reported First Nations status, education, income and unemployment affected an outcome of diabetes (36). The authors found that rates of diabetes were highest in areas of Winnipeg with the highest concentration of Aboriginal peoples. However, these areas also had the lowest socioeconomic factors, which a regression analysis later confirmed to be more predictive of a diagnosis of diabetes than did an Aboriginal status. This suggests that ethnicity alone is not the sole contributor to rising rates of chronic illness in urban environments, but rather social and political factors may be a significant factor as well. Given the small number of observations included in the regression analysis, the results from this study are not necessarily externally valid to the urban Aboriginal population living in all of Canada.

The Our Health Counts (OHC) survey data used for this report listed barriers to accessing health care and asked urban self-identified First Nations respondents how many of these they encountered when trying to access health care in the past 12 months (Table 2). Questions ranged from doctor availability, to coverage of transportation or medical costs, or to whether the respondent felt their health care provider was adequate or not. In addition to health access barriers, explanatory variables related to the social and physical health of First Nations individuals will be included in the analysis. Further explanatory

variables included in the analysis will be access to food, access to housing and social economic factors.

2.6 Explanatory Variable: Access to Housing

In 1991, the Royal Commission Report on Aboriginal Peoples (APS) compared housing condition of on reserve and off reserve Aboriginal peoples living in Canada, and reported that the majority lived in over crowded homes, most in need of some kind of repair (1). In 2001, the APS indicated that 53% of urban Inuit peoples live in crowded conditions, compared to 7% of non-Aboriginal peoples living in Canada (1). Aboriginal people in Canada tend to live in poorer housing conditions and the rate of mobility among the off reserve Aboriginal population in Canada is higher compared to the non-Aboriginal population (7). Between 1991 and 1996, 70% of Aboriginal peoples living in urban centers changed residences and of those who moved, 45% moved within the same community (7). In the OHC survey, the housing variable was characterized as either stable (no moves within the next 5 years), relatively stable (2 or fewer moves in the past 5 years) and unstable (3 or more times in the past 5 years). Moreover, 54% of respondents in the OHC survey reported moving at least three times in the past five years (37). When comparing this to a 2006 census of Hamilton, which indicated that 60% of non-first Nations residents had lived at the same residence 5 years ago, the rate of moving among the First Nations Hamilton population is exceptionally high (37).

2.7 Explanatory Variable: Access to Food in the last 12 months

There is a high prevalence of poor diet among the Aboriginal population in Canada (28). For First Nations youth in Ontario, the mean intake of fruits and vegetables was significantly less than non First Nations children in Ontario (38). Only 22% of

respondents from the OHC survey reported always having enough of the kinds of food they wanted to eat (37). Access to food is a social construct, which is of particular interest to the Aboriginal community partners who align their interests with this research study. The variable associated with access to food in the Our Health Counts survey is divided into four categories, focusing on if a respondent had enough food to eat and if it was the kinds of food they truly wanted to eat.

2.8 Explanatory Variable Socio-economic status (SES) indicators: Education and Income

Both income and education can serve as indicators for socio-economic status (SES), which in turn can significantly predict an individual's health outcome (39, 40). Inadequate education can have a significant impact on SES status later in life, as a poor education does not provide individuals with sufficient skills for a competitive labour market, resulting in low paying jobs (41). Among Aboriginal children, there are high rates of high school dropouts, resulting in reduced literacy and employment rates later in life, and an overall reduced SES level (41). Research has indicated that as household income increases, the proportion of people reporting a poor or fair health outcome decreased (28). In a study of off reserve Aboriginal populations in Canada, the proportion of individuals reporting a poor health outcome decreased as SES status increased (28). According to the OHC survey data, 57% of the sample population had not completed high school, providing insufficient variability to be included as a potential covariate in this analysis (37). In this study, income has multiple categories that can be used, for example, 78% earned of those interviewed for the OHC survey earned less than $20,000 annually and 18% earned less than $4999 annually. In this sample, given the larger

variability of the income categories, this variable will be the primary indicator of SES within the urban First Nations population.

2.9 Conclusion

Upon reviewing the literature on urban Aboriginal peoples living in Canada, despite a recent emphasis on Aboriginal health, it is evident there is still a substantial gap in the literature that looks at health access variables in an urban context, and their impact on the cardiovascular health of the urban Aboriginal population. Existing literature that examines the health access variables for the urban Aboriginal population is generally limited in that study conclusions are usually based on a very small sample size, or on an analysis of census data, which research has indicated to be unrepresentative of the Aboriginal peoples living in Canada. Survey and census data on Aboriginal peoples in Canada is relatively limited or unreliable, resulting in a lack of truly comprehensive health data for Aboriginal peoples in Canada. This limits assessments on the health determinants and health barriers that are known to exist within this population. The unique sampling design of the Our Health Counts Research project utilizes a respondent driven sampling method, which allows for a more valid and unbiased representation of the urban First Nations community in the city of Hamilton. Furthermore data was collected in a manner that was respectful to all self-identified First Nations, Métis and Inuit respondents, and health access barriers were explored in greater detail in this study. This lack of research on the relationship between health access risk factors and diabetes in the urban Aboriginal community motivates this project and we hope that the results of this study can better inform health policy in the urban Aboriginal community.

Chapter 3: Methods

Through the use of advanced regression models, the objective of this thesis is to examine health access risk factors and their association with the prevalence of diabetes in an urban First Nations population. All data for these analyses were obtained from Our Health Counts, a study of the urban First Nations population in Hamilton, ON. Given the methodological advancements required for this kind of analysis, a review of the data and a description of the proposed regression models for analysis are detailed below. For reference, all statistical analyses were performed using SAS version 9.4 and the R programming environment.

3.1 Data

All data were collected from a total of 790 respondents, 554 adults and 236 children, from December 2009 to April 2010. To participate in the Our Health Counts study, all respondents had to meet the established inclusion criteria that they were: 1. Residents of the city of Hamilton; and 2. Self-identified as a First Nations/Native/Indian person. Adults were 18 years or older, and health data were collected for children under the age of fourteen from their parents or guardians. The Our Health Counts study used a community-based research approach (42), actively involving First Nations community members with the design and implementation of the project, to ensure that the culture of the First Nations participants was respected and that all findings would be made accessible to the community members. The reported prevalence of diabetes in the adult population of self-identified First Nations adults living in the city of Hamilton was 15.6% (95% CI. 11.2% to 21.2%) (37).

3.2 Respondent-Driven Sampling (RDS)

RDS is a form of chain referral sampling that is traditionally used to collect data from hidden or marginalized populations that cannot be reached using traditional sampling techniques (8). Such populations are often hesitant to engage in research as they may face potential legal ramifications or persecution based on their association with these marginalized groups (8, 42). Historical examples include populations of injection drug users, transgender individuals or men who have sex with men (8, 43, 44). Traditional chain referral sampling to access these hidden populations, such as convenience and snowball sampling, are prone to various forms of bias, including bias that may have been introduced into the sample due to the choice of initial recruiters and location (8). RDS limits any selection bias that may be introduced into the sample, due to the non-random selection of initial respondents, or "seeds", that start off recruitment of their peers into the sample (9). Heckathorn et al. (8) has shown that, as recruitment chains grow longer and the sample size increases, so does the composition of individuals in the RDS sample. After a large number of waves have passed, respondents no longer share any characteristics with the initial respondents, or seeds. In the Our Health Counts study, ten individuals were identified through the De dwa da dehs ney>s Aboriginal Health Access Centre as potential seeds, six of which volunteered to do so after learning about the potential benefits of this research for urban First Nations health. In RDS, each seed is provided with a fixed number of recruitment coupons to recruit their peers into the study (8). For the Our Health Counts study, each seed received three coupons. Seeds serve to recruit subjects for wave 1, who in turn recruit wave 2. This process continues in waves, until a predetermined sample size is reached. The guidelines of Salganik (45) were

followed for sample size estimation, which recommends that the sample size recruited through RDS should be twice as large as the calculated sample size using simple random sampling.

Furthermore, RDS employs a dual incentive system, where individuals are rewarded for not only participating in the study, but also for each person they recruit to participate in the study (46, 47). The dual incentive system employed by RDS reduces the bias associated with volunteerism, where a certain number of people participate more readily than others, and from masking, where participants are hesitant to reveal personal identity information about their peers to researchers (9). The use of incentives in the Our Health Counts study was carefully considered, as historically, the use of incentives has been abused to manipulate First Nations peoples to participate in research that was harmful to their health. The incentives used in this study were mindful of the historical context of First Nations research and this study was designed in partnership with First Nations community members to ensure all results from this study would empower the First Nations community and it's members (37).

After distributing their coupons, respondents can inform peers about the study, who can in turn decide on their own whether or not they would like to participate (9). The respondents who informed them of the study present them with a numbered coupon, which they present to the researchers before participating, thereby allowing network referral patterns to be mapped out as recruitments tress (Figure 1). Unlike traditional snowball sampling, RDS can provide asymptotically unbiased estimates if the referral chains are long enough (8, 43). Bias is assumed to be negligible based on the assumption that respondent ties within the population to one another are reciprocal, all sampling

occurs with replacement, respondents can accurately report their network size and peers recruit from their social networks randomly and every member of the sample has an equal chance of being recruited into the study (9). However in real life examples, it is unlikely that all potential members of a hidden population have an equal chance of being recruited, or that personal network sizes are always accurately reported (47, 48). To adjust for the increased likelihood of recruiting people with larger social networks, individuals within the RDS sample are inversely weighted in accordance with their social network within the community. RDS recruitment chains proceed as a first order Markov process, in which recruitment into the study typically only depends on the current recruiter, and is independent of pervious influences. Based on this Markov process, it is estimated that an equilibrium state can be reached after 4-6 waves of participants (9).

The use of RDS to examine important public health problems in hidden or hard to reach populations is growing, despite the fact that little investigation towards these methodological complications has been done. Besides estimating population prevalence, there is little validation on the use of other models with RDS data (48). Thus one of the objectives of this study is to examine appropriate statistical regression models for RDS and determine which method provides the most appropriate effect estimates, which could aid future research that employs RDS as a means to examine the health of hidden populations.

3.3 Statistical Challenges and Proposed Methods

Generalized Linear Mixed Models

Generalized linear models (GLM's) are extensions of the general linear model, however in GLM's the response variable can follow a non-normal distribution. Examples

of GLM's include the logistic regression model and the log linear model, where the response variables follow a binomial probability distribution and poisson distribution, respectively (50). Key assumptions of a generalized linear model are that observations are independent, the mean of the observation is a linear function of the covariates and the variance of the observations is constant (50). However, given the complex designs of some research, data may be hierarchical or clustered, which may mean that observations are no longer independent and may be correlated (49).

A statistical model that accounts for the effects of clustering, can provide more valid confidence intervals, significance tests, and may be more conservative when compared to statistical tests that ignore the effects of clustering (51). To account for nesting or the presence of hierarchies within a data set, a mixed effects model can be utilized. An extension of GLM's, generalized linear mixed effects models (GLMM's) incorporate both the fixed and random effects of a data set (50). The fixed effects component of the model refers to the point estimates of responses in the group, which are usually of primary interest for the researcher (50). The random effects of each subject are assumed to follow a distribution that can be accounted for with a covariance model component (50). The random effects of a model can account for the presence of potential correlation that exists between individuals in the data set. Linear mixed modeling can produce results that are significantly different from results attained through general linear modeling, by adjusting point estimates for the presence of correlation within the data (49). General linear mixed models can be used on data sets where the observations are hierarchical, and multilevel models can specify cross level interactions between variables at different levels (49). Clustering of observations within groups can lead to correlated

error terms and biased estimates of the parameter (49). In clustered designs, subjects are nested within units, including schools, hospitals or neighbourhoods (51). Clustering can lead to correlation in the data. By incorporating the structured patterns of correlation into their analysis, general linear mixed models (GLMM's) allow for the calculation of more valid estimates of the fixed effects, by accounting for correlation between subject responses (52).

For GLMM's with dichotomous outcomes, a mixed effects logistic regression model is typically used. A link function, g, relates the mean of the data to the linear combination of fixed effects, $g(E(y)) = Xb$, where y is the outcome and Xb is a linear combination of fixed effects. This study utilizes the log odds, or logit link function, where $g = \log_e (p/(1-p))$, where p is the probability of the outcome. This is typically used for logistic regression with binary outcomes. A generalized linear mixed model follows the equation $y = XB + Zv + e$, where y is the outcome variable, X is a matrix of predictor variables, B is a vector of fixed effects regression coefficients, Z is a matrix of random effects associated with X and v is a matrix of the random components associated with B. The variable e represents the residuals, or the remaining part of v that is not yet accounted for by the rest of the model. With any traditional GLMM, the variance is represented by Var $(Y) = A^{(1/2)}VA^{(1/2)}$ where A corresponds to a diagonal matrix and contains the variance functions of the model, and V is a block diagonal matrix of variance components, specified for the correlation structure.

In the Our Health Counts data set, correlation can occur along the recruitment tree and through a shared recruiter. Figure 2 represents the proposed nested correlation structure for a single recruitment tree (53). Respondents who were recruited from the

same seed may be correlated by an amount (r), as well as those recruited by the same individual in a shared recruiter cluster (s). To account for this correlation, a generalized linear mixed model approach is proposed to include both the random and fixed effects to adjust for this correlation. Furthermore, an appropriate correlation structure must be developed that truly captures the existent correlation in the data. The appropriateness of the selected covariance structure can impact overall model fit, parameter estimates and their standard errors (54). Covariance structures attempt to model all of the variability in the data, which cannot all be explained by the fixed effects, and therefore must be carefully selected to obtain valid inferences for the parameters of the fixed effects. There is no straightforward way to identify the most suitable covariance model (55). If a covariance model is too simple, and does not account for correlation in the data set, this can lead to an increased likelihood of Type 1 errors (55). For example, incorrectly assuming compound symmetry can also lead to inflated Type 1 errors (55). By defining a specific covariance matrix for the model's random components, these parameters can account for any correlation in the data. The correlation structure used to address correlations within the Our Health Counts data will be the first-order autoregressive moving average structure [ARMA(1)]. In some cases where the first-order autoregressive moving average structures [ARMA(1,1)] failed to converge, the first order auto regressive model (AR[1]) correlation structure was used instead. In first order auto regressive correlation [AR(1)], the current value of correlation is dependent only on the immediate proceeding value. It is a covariance structure model that is comparable to the postulated model of correlation for this data set (Figure 2) (53). During the autoregressive process in this correlation structure, the magnitude of correlation

decreases exponentially with distance and a steady decay in correlation is observed over time or with increasing distance between observations (55).

Other Analysis Procedures: Survey Methodology

Two functions utilized in SAS will be the SURVEYFREQ AND SURVEYLOGISTIC functions. SURVEY procedures in SAS provide information on statistical analyses for complex sample survey data. SAS traditionally assumes samples are drawn from infinite populations, and in cases where this is not applicable, special considerations must be made when conducting an analysis on this type of data (56). The SURVEY procedures in SAS allow for the complex sample design of studies to be taken into account, and can adjust for stratification, clusters or unequal weights within the sample data (57). In a simple random sample, every individual in the population has an equal chance of being selected and the selection of individuals is independent of each other (56). This kind of sampling is becoming increasingly rare, as there is a lack of adequate sampling frames for every target population through which to randomly choose respondents from. Obtaining a single, unbiased, sample that is representative of a target population can be challenging, especially if this population is hidden or marginalized (56). Therefore the use of complex survey designs, which may rely on peer social networks, is growing. Social networks in these populations are not random and contain patterns of connectivity between respondents that must be accounted for. Individuals with larger social networks have a greater chance of being recruited into these studies, violating the assumption of equal probability of being sampled (58). In surveys where no large sampling frame has been established for the target population, such as a hidden or marginalized population, respondents must be drawn from clusters, or groups of

respondents who are close to one another. As a result, observations within clusters are not expected to be statistically independent of one another but rather are correlated with one another within the cluster (59). If observations cannot be assumed to be independent, the potential of clustering must be considered in the analysis. Parameter estimates from samples that include clustering are less precise and standard errors are larger, than compared with a simple random sample, because with clustering there are two sources of variability to consider; variability between respondents within a cluster and variability between the different clusters (59). Failing to account for clustering can lead to falsely narrow confidence intervals and falsely low p values (59). In the Our Health Counts study, respondents who shared the same recruiter may be clustered (53). The effects of clustering and the size of social networks will be accounted for using the survey procedures in the statistical software SAS version 9.4.

3.4 STATISTICAL PROCEDURES
PROC SURVEYFREQ

The SURVEYFREQ procedure can compute population based prevalence estimates of health outcomes. SAS 9.4 allows for odds ratios and relative risks to be estimated using the SURVEYFREQ procedure. SURVEYFREQ will be used to look at bivariate associations between health access risk factors and diabetes and to produce 2x2 tables that will produce unadjusted odds ratios and 95% confidence intervals (57).

PROC SURVEYLOGISTIC

PROC SURVEYLOGISTIC in SAS is a procedure that can be used to perform survey-based logistic regression in SAS statistical software. PROC SURVEYLOGISTIC fits linear logistic regression models using maximum likelihood and is capable of

incorporating sample design into the analysis (57). Using the CLASS statement in PROC

SURVEYLOGISTIC it is possible to identify categorical variables in the analysis.

Sample design information can be specified in this function with the STRATA,

CLUSTER and WEIGHT statements. The STRATA statement involves samples within

strata's, or non-overlapping groups in the data. The CLUSTER statement accounts for

the effects of clusters in the study, which are groups of sampling units (57). Not

accounting for clusters in the data can result in a loss of precision for the final result. The

WEIGHT statement accounts for the unequal probability of sampling in the data set (57).

Link functions are also available for PROC SURVEYLOGISTIC and for this study the

generalized logit function (glogit) is used.

PROC GLIMMIX

A major function for fitting GLMM's in SAS is PROC GLIMMIX, which unlike

PROC SURVEYLOGISTIC can fit random effects into the model, as well as fit statistical

models with correlations (57). To use PROC GLIMMIX, a CLASS, MODEL and

RANDOM statement must be specified. The CLASS statement identifies the categorical

variables, the MODEL statement specifies the fixed effects, while the RANDOM

statement specifies the random effects components. The _RESIDUAL _ statement

accounts for over dispersion, which is the presence of greater variability in the sample

data than what is expected. In GLIMMIX, in the RANDOM statement, the _RESIDUAL

_ statement can estimate the dispersion coefficient and specify the appropriate covariance

structure. In this study, we specified the effects of clustering due to a shared recruiter, for

each respondent as an R side effect with a first order autoregressive covariance structure,

(AR[1]) by using the _RESIDUAL _ statement (57)

3.5 Confounding Variables in Analysis

Confounding Variable: Body Mass Index (BMI)

BMI is a well-known risk factor for diabetes, hypertension and other cardiovascular diseases (60). Rates of obesity and overweight in First Nations populations are increasing at an alarmingly rate, more so than in the non First Nations population living in Canada (60, 61). Rates of obesity are higher among First Nations youth in Canada compared to non-First Nations youth (61). BMI is calculated as the participant's weight (kg) divided by their height (m^2) and will be included as a continuous confounder in the multivariate models for this analysis. Note that height and weight measurements were self reported and thus may be subject to recall bias.

Confounding Variable: Physical Activity

The OHC survey asked participants the number of days per week the participant completed at least 30 minutes of moderate to vigorous activity. The recommended physical activity guidelines established by the Public Health Agency of Canada for adults in 30 minutes of vigorous activity, 4 or more times per week (62).

Confounding Variable: Smoking Status

Respondents will be categorized as a current smoker, former smoker, or non-smoker. Smoking is associated with chronic cardiovascular conditions and rates of smoking were calculated to be twice as high among urban Aboriginal peoples 15 years or older, compared to non-Aboriginal peoples (4).

Confounding Variable: Alcohol Consumption

The OHC survey data includes data on drinking behaviors for the previous 12 months. Heavy drinking can contribute to an increased risk of metabolic disease (63, 64)

thus models will include the number of times a binge drinking episode occurred (number

of times 5 or more drinks on one occasion) in the past 12 months.

Chapter 4: Manuscript

Abstract

The purpose of this study was to examine the relationship between health access variables and diabetes in an urban First Nations population living in Canada. Data were collected from a self-identified urban First Nations population, using respondent driven sampling (RDS). As no clear approach for regression modeling of RDS data is available, various logistic regression modeling approaches, including survey procedures and linear mixed models were performed to explore the relationship between diabetes and health access risk factors of interest, including access to healthcare, food, housing and socioeconomic factors. After controlling for confounders using multiple approaches, feeling health care provided was not culturally appropriate was significantly associated with an increased odds of diabetes (12.70, 95% CI 2.52, 57.91), while there was some potential evidence of associations between not having a doctor available in the area, feeling that health care provided was inadequate and if health care services were not available in the area. Establishing more health care services that integrate First Nations cultures and traditions into their care could improve the health of First Nations peoples living in urban environments.

Keywords: First Nations, diabetes, health access,

Introduction

In the past few decades, there has been a dramatic increase in the number of
Aboriginal peoples in Canada moving to urban centres (1). Despite their growing
urbanization, health data on Aboriginal peoples living in an urban space is limited.
Research indicates that the Aboriginal peoples in Canada suffer from substantial health
disparities, compared to non-Aboriginal peoples living in Canada (2), and the extent to
which these disparities impact the overall health of those living in an urban space has yet
to be explored in detail. In 1950, 7% of self-identified Aboriginal peoples living in
Canada lived in urban areas (1). By 2006, this number had increased to 54% (3, 4). Of the
self-identified First Nations people who indicated that they lived off reserve, 76% lived in
an urban area (4). The Aboriginal populations in Canada suffer from a disproportionate
number of health disparities, including an abnormally high prevalence of hypertension,
diabetes and cardiovascular diseases (2). The prevalence of diabetes is three times higher
among Aboriginal peoples in Canada, compared with non-Aboriginal peoples (5) and
cardiovascular diseases are the most common cause of death for urban Aboriginal men
and women aged 25 years or older (3), despite their recent decline among the non-
Aboriginal population (6). These health disparities may be reflective of underlying social,
cultural and political inequities within the Aboriginal population living in Canada.
Research on Aboriginal peoples has shown that the majority of the inequities faced by
this population can be traced back to the discrimination and violation this group of
peoples endured during European colonization (6). Research suggests that the harsh
effects of colonization and discrimination the Aboriginal peoples faced in the past,
currently manifests itself with higher rates of suicide, injury, substance abuse and poor
health outcomes disproportionately suffered by the Aboriginal peoples living in Canada

(6). The inequities experienced by Aboriginal peoples in Canada are further complicated by the growing urbanization of this population, as Aboriginal peoples incur new social and health access barriers in urban spaces (7).

Furthermore, census data on the Aboriginal peoples in Canada is sparse and often unreliable (8). The lack of comprehensive health data on this growing urban population hinders the implementation of policy changes targeting urban Aboriginal peoples, or for the health determinants of this population to be explored in greater detail (8). Population level data from Canada has shown that Aboriginal peoples in urban areas utilize fewer community based health support programs, and have higher rates of non-emergent admission to hospital emergency rooms (9); an indicator of lack of access to primary care services. Research has indicated that individuals who feel marginalized, uncomfortable with community based health services or who do not have access to a primary care provider, are more likely to seek help at emergency rooms for non-emergent care (9). Furthermore, research on Aboriginal groups in Canada, New Zealand, the U.S. continue to show that the effects of colonization impact access to care for many First Nations groups (10). The harsh effects of colonization have fostered a deep distrust in many government agencies, making the utilization of mainstream health services psychologically stressful for many Aboriginal peoples (10).

Using data collected through respondent driven sampling (RDS), the objective of this study is to examine the relationship between explanatory health access variables and a self-reported physician diagnosis of diabetes, while also adjusting for the presence of confounders, including age, sex, BMI, physical activity levels, drinking habits and smoking status. Moreover, as no clear statistical methods exist for the multivariable

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analysis of RDS data, this paper serves as a comparison of two competing statistical approaches that are commonly used for the multivariable analysis of RDS data.

Methods

Data Collection

Data collected for this study were obtained from the Our Health Counts project. A total of 790 respondents, 554 adults and 236 children, participated in the study between December 2009 and April 2010. Eligible participants lived within the city of Hamilton, ON and self identified as a First Nations or Native person. Respondents who completed the survey received a financial incentive ($20), as well as $10 for every eligible participant they recruited into the study. Ninety-five percent of adult respondents agreed to provide their Ontario health card number so that their emergency room use, hospital admission rate and use of preventative screening programs could be linked through the Institute for Clinical Evaluative Sciences (ICES). Demographics of the adult respondents are provided in Table 1. All adult participants could opt in or out of this ICES linkage. Ethics approval was granted from the ethics board at the Centre for Research on Inner City health at St. Michael's Hospital, in partnership with the Ontario Federation of Indian Friendship Centres and De dwa da dehs ney>s Aboriginal Health Access Centre. Health access variables explored in this study are outlined in Table 2. Access variables considered for this study include access to healthcare in the past 12 months, access to food in the past 12 months, access to housing and income. The presence of diabetes was measured by self-reported physician diagnosis.

Respondent Driven Sampling

Respondent driven sampling (RDS) has been proposed as an effective means to access a population that is otherwise hidden or marginalized, preventing them from participating in common survey methods (11). In RDS, respondents are given coupons to hand out to their peers to recruit them into the study. Recruitment begins with the selection of initial respondents, or "seeds" to recruit their peers into the study. A copy of the recruitment tree for the Our Health Counts study is shown in Figure 1. Unlike traditional chain referral sampling methods, RDS is capable of reducing bias that may have been introduced into the sample due to the non-random selection of initial respondents and location, after a minimum number of recruitment waves is achieved (11). Probability of selection in respondent driven sampling is dependent on the individual's social network size within the hidden population (12). Because individuals with larger network sizes have a greater likelihood of being recruited into the study, respondents are asked to estimate the size of their personal social network and responses are weighted accordingly (13). Furthermore, RDS is used to estimate population level proportions. Through the use of computer simulations, Salginek and Heckathorn (13) show that population proportion estimates determined through RDS are asymptomatically unbiased, no matter how seeds are initially selected and comparable to actual population proportions.

Regression Models

As no clear method for the multivariable analysis of RDS data is available, two approaches both grounded in statistical theory were used to examine the relationship between diabetes and health access variables of interest. Weighted logistic regression

models were calculated using the functions PROC SURVEYFREQ and PROC

SURVEYLOGISTIC in SAS version 9.4 (14). Data collected through RDS is complex

(15), as recruitment among peers has a tendency to occur in clusters (16) and responses

need to be appropriately weighted to account for unequal sampling probabilities. The

simple assumption that all respondents are independent of one another is no longer

applicable as correlation between respondents must be accounted for. The second

approach is through generalized linear mixed models as they can naturally be adapted to

include the correlation structure of interest and appropriate weights. The GLIMMIX

procedure in SAS was used to model this approach. Figure 2 represents the proposed

correlation structure for a recruitment tree in the RDS sample (17). In this model, r

corresponds to the correlation of individuals recruited by the same respondent and s

accounts for correlation within the same cluster. This proposed correlation structure was

used, but as it failed to converge due to sparse cells, a first order auto regressive model

(AR[1]) was used to adjust for correlation in the generalized linear mixed model. Similar

to the proposed correlation model, this model assumes the magnitude of correlation

decreases exponentially with growing distance between observations (18). Weighted

linear mixed models were used to adjust for unequal sampling probabilities. All models

were adjusted for known confounders including age, sex, BMI, number of days per week

engaging in vigorous physical activity for at least 30 minutes, alcohol consumption

(number of times 5 or more drinks were consumed in one occasion) and smoking status

(current smoker, former smoker, non smoker).

Odds ratios (OR) and their 95% confidence intervals (OR, 95% CIs) were

generated from each model. The unadjusted association of each health access risk factor

and diabetes were reported, as well as weighted associations that adjusted for the confounders age and sex in a simplified adjusted model and a fully adjusted model for age, sex, BMI, physical activity level, drinking episodes and smoking status.

Results

Table 3 shows the unweighted and unadjusted bivariate association between health access risk factors and diabetes. Table 4 shows the weighted association between health access risk factors and odds of diabetes, after adjusting for sex and age. In the SURVEYLOGISTIC model, there was a statistically significant relationship between increased odds of diabetes and not being covered by non-insured health benefits (3.66, 95% 1.32-10.15) and prior approval for coverage under non-insured health benefits (NIHB) being denied (3.48, 95% 1.36-8.87). In the GLIMMIX model, there was a statistically significant relationship between increased odds of diabetes and the waiting list to access health services being too long (2.00, 95% 1.19-3.38), not being covered by non-insured health benefits (3.66, 95% 2.00-6.70), prior approval for coverage under non insured health benefits (NIHB) being denied (3.47, 95% 1.81-6.67) and income (1.11, 95% 1.03-1.19).

Table 5 shows the weighted association between health access risk factors and odds of diabetes after adjusting for sex, age, BMI, level of physical activity, drinking behaviour and smoking status. In the SURVEYLOGISTIC model, a statistically significant relationship was found with an increased odds of diabetes and feeling that healthcare provided was inadequate (8.54, 95% 1.40-53.40), respondents feeling healthcare provided was not culturally appropriate (17.87, 95% 2.90-110.24) and income (1.29, 95% 1.03-1.63). In the GLIMMIX model, the health access risk factor feeling

health services were not culturally appropriate was significantly associated with an increased odds of diabetes (12.70, 95% 2.52-57.91). The health access risk factors could not afford childcare costs and chose not to see a health professional failed to converge in the GLIMMIX model due to sparse cells.

Discussion

Literature on the health of urban Aboriginal peoples living in Canada is sparse, and this study has the potential to provide new insight into the health of this population, by examining the relationship between health access risk factors and diabetes in an urban setting. The use of various multiple logistic regression models to examine the impact of health access risk factors on diabetes were compared to test the methodological rigour and robustness of regression models applied to RDS. After adjusting for confounders, feeling that health care services provided were not culturally appropriate was significantly associated with an increase in odds of diabetes. This result corroborates with previous research that has emphasized the importance of culturally appropriate health services in improving the health of urban First Nations peoples living in Canada. Culturally appropriate services are services that create a social space where the cultural beliefs of the people utilizing the service are being respected, by actively employing the use of traditional language, traditional healers, the work of elders and traditional healing practices (19). Research has shown that urban Aboriginal peoples have a strong desire to seek out more culturally appropriate services (20); specifically those health services that acknowledge the longstanding damage colonization has inflicted on their values of self-worth, self-respect; both of which have a substantial impact on overall feelings of health (21, 22, 23). A greater emphasis on culturally appropriate services, which honour

Aboriginal cultures and traditions, can enhance teaching for urban Aboriginal peoples to reclaim control over their health again, which could translate into better health in the long term. The implications of health services that are more culturally sensitive for urban Aboriginal peoples in Canada can extend beyond just metabolic health, as Stone et al. (24) found a strong link between participation in traditional indigenous activities and the cessation of alcohol abuse. Furthermore, the Royal Commission on Aboriginal Peoples (25) suggests that depression can also be reduced with a greater emphasis on culturally appropriate services that targets urban Aboriginal populations. The desire for more culturally appropriate health services could also potentially be achieved with the integration of both traditional Aboriginal culture and traditions into the modern health care system (26). No longer should urban spaces and Aboriginal cultures be regarded as mutually exclusive, but rather a greater emphasis on integrating the two could achieve maximum health benefits for Aboriginal peoples living in an urban space.

Furthermore, the lack of culturally sensitive health services in urban settings could be attributed to judicial discrepancies between the Provincial and Federal governments. The Federal government is responsible for overseeing the health policies affecting First Nations peoples living on reserves (5). Federal jurisdiction over the health of First Nations peoples does not extend beyond the reserves, and when First Nations peoples migrate to cities, they find themselves no longer able to access health services as readily. In the Our Health Counts Study, the health access barriers having non insured health benefits (NIHB) denied as well as having prior approval for services under non-insured health benefits (NIHB) denied, were significantly associated with an increased odds of diabetes after adjusting for age and sex and indicated a trend towards significance

after adjusting for further confounding variables. These health access barriers are directly associated with government policies and may be reflective of the inability to obtain the same access to health care goods and services in an urban space, as compared to on a reserve. Stronger co-ordination between both the provincial and federal government health policies is needed to ensure this population can thrive in any environment.

The barrier feeling that healthcare provided was inadequate exhibited a potential association with increased odds of diabetes (8.19, 95% 0.97-69.31) after adjusting for confounding variables. The belief that the health services they were accessing were inadequate could be attributed to poor doctor-patient communication between Aboriginal peoples and doctors they encounter in the healthcare system. The level of communication between a doctor and patient can have a significant effect on their relationship and the patient's trust in the health care provider (27). For Aboriginal peoples living in Canada, a complex history of social factors may be impacting their health overall as well as their ability to openly share these experiences with a health care provider (9) and literature has indicated that Aboriginal peoples living in Canada, the USA and Australia endure substantial miscommunications and misunderstandings with their doctors (28). Patients who do not report good experiences with their doctors are more likely to have a critical outlook of their experience. In this urban self-identified First Nations population, the use of hospital emergency rooms was significantly higher than the non First Nations population, which can be indicative of a lack of trust or access to adequate preventative services (29). The mis-use of emergency room for non-emergent needs has been linked with marginalized populations, who are unable to access care for their health needs otherwise (9). The barrier of not being able to locate a doctor in the area also

demonstrated a potential association with increased odds of diabetes after adjustment for confounders (4.07, 95% 0.98-16.84). This finding corroborates with the findings from the Our Health Counts study that First Nations peoples living in the urban area of Hamilton, Ontario were significantly more likely to use the emergency room for non-emergent needs compared to the non First Nations population living in Hamilton (30). The overuse of the emergency room for non-emergent needs could be in indication of a lack of adequate access to a primary care physician. Furthermore, according to the Aboriginal Peoples Survey, the number of off reserve First Nations and Aboriginal peoples in Canada who reported seeing a doctor in the previous year was significantly lower than the non First Nations population in Canada (25).

One limitation of this study is that the data collected through the Our Health Counts Project are cross-sectional, therefore no causality can be inferred. Upon initial review of the data it could be inferred that the lack of access to culturally appropriate health services may contribute to increased incidence of diabetes; however this could be an example of bias by indication where those individuals with diabetes are seeking out medical care more often and are therefore more likely to find these health services less culturally appropriate. However, even though causality cannot be inferred, a significant association between individuals with diabetes and those seeking out medical care can be inferred. Furthermore, the presence of diabetes had to be confirmed from a health care professional. Because the study population underutilizes health services, the prevalence of diabetes may have been underreported in this population. Another limitation is the lack of a clear method for regression modeling using data collected through RDS. Simulation studies are underway and show that the GLIMMIX method using the statistical software

SAS appears robust against Type 1 errors, while the SURVEY procedures may risk an elevated type I error rate. Thus while we are confident in the conclusions of the GLIMMIX approach, Survey methods may be at risk of generating false positives. A strength of this study is the use of RDS to recruit urban First Nations peoples, thus allowing for a more valid representation of the urban First Nations community in the city of Hamilton. Moreover, note that although some variables did not meet the traditional levels of statistical significance in the fully adjusted models, there is still potential for very large effect sizes; illustrating the plausible impact of these variables. The results of this study could provide new insight into the health access barriers First Nations peoples incur in an urban space. Future studies examining the barriers incurred by First Nations peoples in urban spaces in greater detail could provide more insight into the access barriers this population incurs.

Existing literature that examines the health access variables for the urban First Nations population is generally limited as study conclusions are usually based on a very small sample size, or on an analysis of census data, which research has indicated to be unrepresentative of the First Nations peoples living in Canada (30). Surveys and census data on Aboriginal peoples in Canada is relatively limited or unreliable, resulting in a lack of truly comprehensive health data for Aboriginal peoples in Canada (30). This limits assessments on the health determinants and health barriers that may exist within this population. The unique sampling design of the Our Health Counts Research project utilizes a respondent driven sampling method, which allows for a more valid and unbiased representation of the urban First Nations community. Furthermore data were collected in a manner that was respectful to all self-identified First Nations, Métis and

Inuit respondents (31), and health access barriers and their relationship with diabetes were explored in this study. Improving health access services so they are more culturally appropriate for First Nations beliefs and traditions, and implementing more cohesive health policies to ensure First Nations peoples receive adequate health benefits both on and off reserves could improve diabetes outcomes as well as the overall health of First Nations people living in urban centres.

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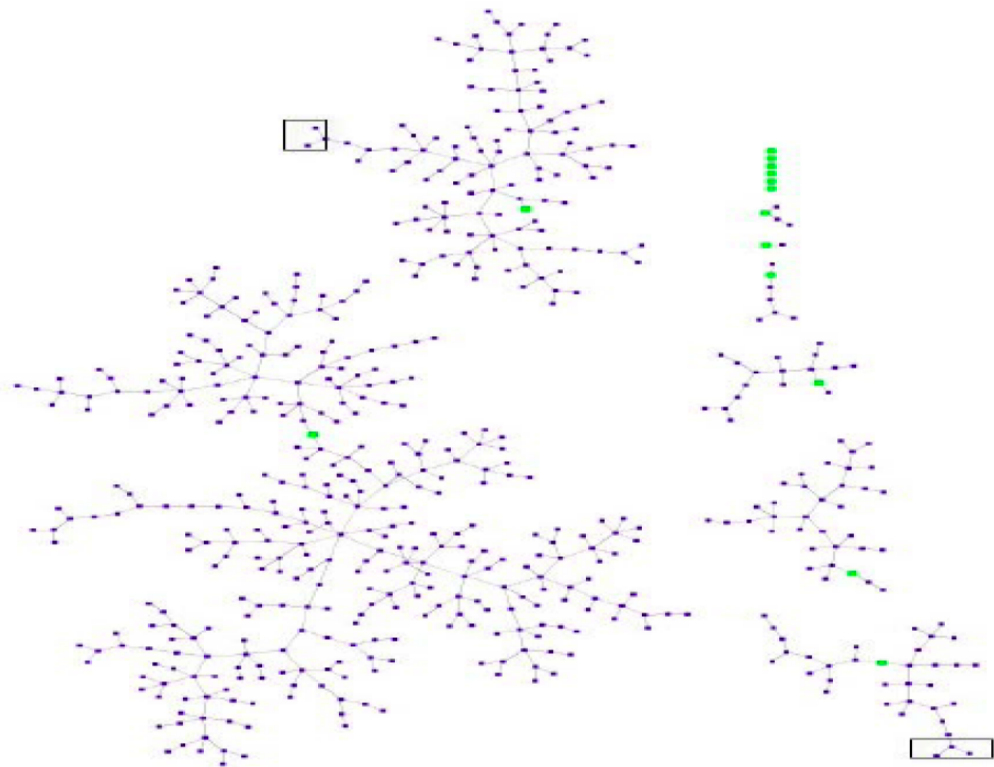
Figure 1: Respondent Driven Sampling (RDS) recruitment tree from the OHC study. Seeds are indicated in green.

	A	B	C	D	E	F	G	H	I
A	1	r	r	r^2	r^2	r^2	r^3	r^3	r^3
B	r	1	s	r	r	r	r^2	r^3	r^3
C	r	s	1	rs	rs	rs	r^2s	r^2s	r^2s
D	r^2	r	rs	1	s	s	rs	r^2s	r^2s
E	r^2	r	rs	s	1	s	rs	r^2s	r^2s
F	r^2	r	rs	s	s	1	r	r^2	r^2
G	r^3	r^2	r^2s	rs	rs	r	1	r	r
H	r^3	r^3	r^2s	r^2s	r^2s	r^2	r	1	s
I	r^3	r^3	r^2s	r^2s	r^2s	r^2	r	s	1

Figure 2: Illustration for correlation for a single respondent in respondent driven sampling. The r parameter denotes a declining level of correlation throughout the tree (solid line) while s denotes the correlation between participants who are recruited by the same individual (dotted line).

Table 1: Demographics of First Nations adults in the Our Health Counts Study

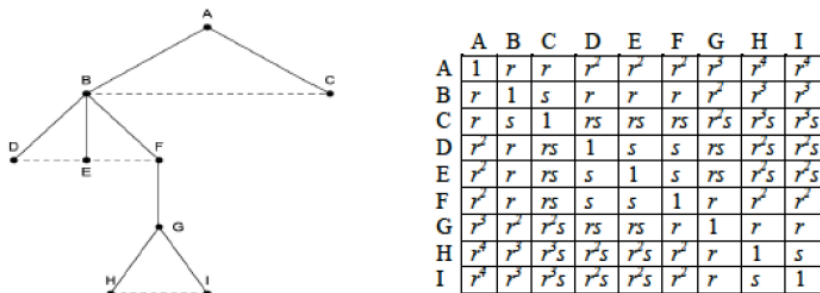| First Nations Adults		N	%	RDS %	95% C.I.
Age on 2010-04-01	18-34	196	37.4	41.9	[34.4, 49.9]
	35-49	197	37.6	36.6	[29.9, 43.1]
	50-64	120	22.9	20.7	[14.7, 26.9]
	65+	11	2.1	0.8	[0.3, 1.6]
Sex	Female	259	49.43	37.6	[29.6, 43.6]
	Male	265	50.57	62.4	[56.4, 70.4]
Income Quartile	Low	376	71.76	73	[66.5, 79.2]
	2	85	16.22	11.8	[7.7, 16]
	3	33	6.3	7.4	[3.6, 10.5]
	4	13	2.48	4.9	[2.5, 9.8]
	High	7	1.34	3	[1.1, 5.4]
	Missing	10	1.91	n/a	n/a
Total		524	100	n/a	n/a
Diabetes Prevalence			15.6		

Table 2: Explanatory Variables from the Our Health Counts (OHC) survey

Variable	Question	Outcome	Survey Question
Access to Health Care	During the past 12 months, have you experienced any of the following barriers to receiving health care?	1. Doctor not available in my area. 2. Nurse not available. 3. Lack of trust in health care provider. 4. Waiting List too long. 5. Unable to arrange transportation. 6. Difficulty getting traditional care. (ie: healer, medicine person or elder) 7. Not covered by non-insured health benefits (NIHB). 8. Prior approval for services under NIHB was declined. 9. Could not afford direct cost of care/service. 10. Could not afford transportation costs. 11. Could not afford childcare costs. 12. Felt healthcare provided was inadequate. 13. Felt service was not culturally appropriate. 14. Chose not to see health professional. 15. Service was not available in my	Section 4.C.3

		area.	
Access to food in the last 12 months	Which of the following best describes the food eaten in your household in the past 12 months:	1. You and others always had enough of the kinds of food you wanted to eat. 2. You and others had enough to eat, but not always the kinds of food you wanted. 3. Sometimes you or others did not have enough to eat. 4. Often you or others did not have enough to eat. 5. Don't Know 6. No Response	Section 1.C.2
Access to Housing	How many times have you moved in the past 5 years?	# of times	Section 1.B.4
Income	For the year ending December 31, 2008, please think of your total personal income, before deductions, from all sources. Please look at these categories and tell me which range it falls into:	1. No Personal Income 2. $1- $4,999 3. $5,000-$9,999 4. $10,000-$14,999 5. $15,000-$19,999 6. $20,000-$24,999 7. $25,000-$29,999 8. $30,000-$39,000 9. $40,000-$49,999 10. $50,000-$59,999 11. $60,000-$69,999 12. $70,000-$79,999 13. $80,000 and over 14. Don't Know 15. No Response	Section 6.C.1

Table 3: Un-weighted analysis between factors related to access to health care and diabetes.

Health Access Variable	SURVEYLOGISTIC	GLIMMIX
	Odds Ratio (95% CI)	Odds Ratio (95% CI)
Doctor not available in my area	0.84 (0.34-2.08)	0.85 (0.49-1.46)
Nurse not available	0.99 (0.38-2.56)	1.00 (0.54-1.86)
Lack of trust in health care provider	1.10 (0.48-2.52)	1.07 (0.63-1.89)
Waiting List too long	1.76 (0.78-3.97)	**1.79 (1.11-2.88)**
Unable to arrange transportation	1.05 (0.44-2.52)	1.04 (0.64-1.70)
Difficultly getting traditional care (ie healer, medicine person, or elder)	0.60 (0.23-1.57)	0.60 (0.28-1.27)
Not covered by Non-insured Health Benefits (ie: service, medication, equipment)	**3.73 (1.33-10.46)**	**3.72 (2.19-6.33)**
Prior approval for services under Non-insured health benefits (NIHB) denied	**4.24 (1.53-11.78)**	**4.28 (2.44-7.48)**
Could not afford direct cost of care/service	1.99 (0.76-5.24)	**1.97 (1.20-3.24)**
Could not afford transportation costs	1.39 (0.60-3.22)	1.42 (0.87-2.32)
Could not afford childcare costs	0.79 (0.26-2.40)	0.79 (0.26-2.41)
Felt healthcare provided was inadequate	1.55 (0.66-3.68)	1.54 (0.91-2.59)
Felt service was not culturally appropriate	2.05 (0.85-4.92)	**1.98 (1.14-3.42)**
Chose not to see health professional	0.99 (0.40-2.46)	0.99 (0.59-1.67)
Service was not available in my area	1.37 (0.56-3.37)	1.32 (0.74-2.36)
Access to food in the last 12 months	0.87 (0.51-1.47)	0.88 (0.68-1.14)
Income	1.11 (1.00-1.22)	**1.11 (1.04-1.18)**
Access to Housing	0.83 (0.47-1.45)	0.82 (0.58-1.15)

Table 4: Weighted analysis of association between health access risk factors and diabetes, adjusted for sex and age.

Health Access Variable adjusted for sex and age	SURVEYLOGISTIC	GLIMMIX
	Odds Ratio (95% CI)	**Odds Ratio (95% CI)**
Doctor not available in my area	0.94 (0.38-2.31)	0.96 (0.53-1.74)
Nurse not available	1.14 (0.42-3.10)	1.17 (0.59-2.30)
Lack of trust in health care provider	1.45 (0.64-3.30)	1.47 (0.78-2.70)
Waiting List too long	1.97 (0.87-4.48)	**2.00 (1.19-3.38)**
Unable to arrange transportation	1.29 (0.54-3.09)	1.27 (0.74-2.19)
Difficultly getting traditional care (ie healer, medicine person, or elder)	0.62 (0.24-1.64)	0.62 (0.28-1.35)
Not covered by Non-insured Health Benefits (ie: service, medication, equipment)	**3.66 (1.32-10.15)**	**3.66 (2.00-6.70)**
Prior approval for services under Non-insured health benefits (NIHB) denied	**3.48 (1.36-8.87)**	**3.47 (1.81-6.67)**
Could not afford direct cost of care/service	1.74 (0.67-4.53)	1.72 (0.98-3.01)
Could not afford transportation costs	1.19 (0.50-2.83)	1.20 (0.69-2.07)
Could not afford childcare costs	1.03 (0.33-3.19)	1.10 (0.34-3.58)
Felt healthcare provided was inadequate	1.16 (0.46-3.00)	1.16 (0.65-2.05)
Felt service was not culturally appropriate	1.26 (0.48-3.29)	1.24 (0.67-2.27)
Chose not to see health professional	1.17 (0.49-2.77)	1.18 (0.67-2.10)
Service was not available in my area	1.62 (0.69-3.80)	1.55 (0.82-2.91)
Access to food in the last 12 months	0.83 (0.51-1.34)	0.85 (0.65-1.11)
Income	1.10 (0.97-1.24)	**1.11 (1.03-1.19)**
Access to Housing	1.01 (0.97-1.06)	1.01 (0.97-1.06)

Table 5: Weighted analysis of association between health access risk factors and diabetes, adjusted for sex, age, BMI, physical activity level, smoking status and alcohol habits.

Health Access Variables adjusted for sex, age, physical activity level, BMI, alcohol use and smoking status	SURVEYLOGISTIC	GLIMMIX
	Odds Ratio (95% CI)	Odds Ratio (95% CI)
Doctor not available in my area	4.06 (0.93-17.77)	4.07 (0.98-16.84)
Nurse not available	0.76 (0.08-6.86)	0.79 (0.13-4.77)
Lack of trust in health care provider	2.05 (0.34-12.36)	2.11 (0.48-9.21)
Waiting List too long	3.50 (0.69-17.71)	3.43 (0.62-18.86)
Unable to arrange transportation	3.98 (0.81-19.44)	4.02 (0.68-23.67)
Difficultly getting traditional care (ie healer, medicine person, or elder)	7.91 (0.76-82.14)	7.92 (0.50-124.63)
Not covered by Non-insured Health Benefits (ie: service, medication, equipment)	1.46 (0.38-5.61)	1.64 (0.36-7.49)
Prior approval for services under Non-insured health benefits (NIHB) denied	1.14 (0.19-6.77)	1.14 (0.22-5.83)
Could not afford direct cost of care/service	1.69 (0.27-10.57)	1.85 (0.35-9.82)
Could not afford transportation costs	0.54 (0.07-4.03)	0.48 (0.06-3.76)
Could not afford childcare costs	<.001	-
Felt healthcare provided was inadequate	**8.54 (1.40-53.40)**	8.19 (0.97-69.31)
Felt service was not culturally appropriate	**17.87 (2.90-110.24)**	**12.07 (2.52-57.91)**
Chose not to see health professional	3.41 (0.64-18.30)	-
Service was not available in my area	7.60 (0.89-65.15)	7.46 (0.97-57.45)
Access to food in the last 12 months	0.38 (0.09-1.59)	0.38 (0.10-1.40)

Income	**1.29 (1.03-1.63)**	1.30 (0.98-1.72)
Access to Housing	0.52 (0.26-1.07)	0.53 (0.18-1.55)

Chapter 5: Discussion

Literature on the health of urban First Nations peoples in Canada is sparse, and this study builds on the existing literature by examining the relationship between health access risk factors and diabetes in an urban population of self-identified First Nations peoples. The effects of health access risk factors were further assessed in the presence of different confounding variables. After adjusting for confounding variables, feeling that health care services accessed in the previous 12 months were not culturally appropriate was significantly associated with increased odds of diabetes (12.70, 95% 2.52-57.91). Certain other health access risk factors displayed potential evidence of association with increased odds of diabetes as well, including not being able to locate a doctor in the area (4.07, 95% 0.98-16.84), feeling health care provided was inadequate (8.19, 95% 0.97-69.31), or if health care service was not available in the area (7.46, 95% 0.97-57.45).

The significance of the relationship between feeling health care services were not culturally appropriate and diabetes supports previous research that has emphasized the importance of culturally appropriate health services in improving the health of urban First Nations peoples living in Canada. In a 2010 report on the health of urban Aboriginal peoples in Canada, culturally appropriate services were defined as services that create a social space where the cultural beliefs of the people utilizing the service are being respected, by actively employing the use of traditional language and communication style, traditional values, traditional healers as well as the work of elders and traditional healing practices (65). Research has shown that urban Aboriginal peoples have a strong desire to seek out more culturally appropriate services (30); specifically those health

services that acknowledge the longstanding damage colonization has inflicted on their values of self-worth and self-respect; both of which have a substantial impact on overall feelings of health (12, 21, 27). The Royal Commission on Aboriginal Peoples (66) specifies that urban Aboriginal peoples in Canada are not only suffering from higher manifestations of physical diseases, but long standing lingering depression as well, resulting from the substantial damage to their self worth and own well being that was inflicted during colonization. This depression is a major contributing factor to their overall health and sense of well-being. A stronger emphasis on culturally appropriate services has the potential to enable urban Aboriginal peoples to reclaim control over their health again, which could translate into better overall long term health. Despite a lack of scientific evidence on the effectiveness of culturally appropriate spaces, anthropologists and Aboriginal persons themselves have spoken out about the importance of culture and First Nations traditions to support their overall health, especially with alcohol and substance abuse problems (65). Research on the importance of culturally appropriate health services on other Aboriginal groups in Australia, Canada and the U.S. have also indicated they are effective at curbing substance abuse problems (67). Access to culturally sensitive health services has the potential to dramatically improve the overall health of the Aboriginal peoples in Canada, by counteracting some of the long-standing damage inflicted by colonization.

In their paper, Mundel et al. (68) acknowledge that Aboriginal cultural approaches towards health differ from the approach used by everyday westernized medicine. In Aboriginal cultures, health is determined through the physical, social and spiritual well being, for not only the individual, but their families as well (69).

Furthermore, many Aboriginal traditional healing practices rely on spirituality, religious ceremony and associations with nature to promote health (68). The association between nature and health has also been described by the Medicine wheel, a widely recognized symbol of indigenous health, emphasizing overall individual mental emotional and spiritual health (68). For Aboriginal peoples in Canada, their perception of health is holistic, involving the mind, body and spirit with community and environment (69). The poor health of Aboriginal peoples in Canada can be traced back to the dissociation from their land and their traditional language this population endured during colonization (18). The destruction of traditional healing practices, and the creation of new health care systems that did not take on a holistic point of view on health, are all contributors to the disparities suffered by Aboriginal populations today. By incorporating more health services that are mindful of the Aboriginal perspective of health, there is the potential for Aboriginal peoples to become more empowered and regain control over their health status (13). To make health services more culturally appropriate will make health services more welcoming, less threatening and more empowering for the Aboriginal individual.

In their report, Philis-Tsimikas et al. (70) have shown that diabetes education programs that are culturally appropriate can have a significant effect on improving health outcomes, but there is limited literature on the effectiveness of implementing programs that utilize traditional cultural approaches to manage diabetes (70). In their study, patients who were enrolled in a culturally sensitive, community based diabetes care management program, saw improvements in their knowledge of the disease, ability to self care and overall health status (70). Diabetes management programs are becoming increasingly popular, as literature is indicating they are associated with improvements in health

outcomes, and are more effective when they incorporate traditional methods unique to a specific culture (71). In their intervention to improve glycemic control among low income self identified Latin Americans with Type 2 diabetes, Rosal et al. (72) found that interventions that were more culturally tailored improved diabetes control and self-efficacy among participants.

The lack of culturally specific health services for Aboriginal peoples living in urban areas can be attributed to judicial discrepancies between both the Federal and Provincial levels of government, as there is no universal provincial or national policy that encompasses urban Aboriginal peoples (3, 65). Traditionally, the Federal government has claimed responsibility over the health policies affecting Aboriginal populations in Canada living on reserves. However First Nations peoples that move off reserves to urban areas are neglected (65). Health services in an urban space no longer fall under federal jurisdiction, and often the urban municipal jurisdictions are left to oversee their implementation for this population (3). For example, non-insured health benefits (NIHB) are health benefits created to assist First Nations peoples accessing services in Canada (73). However a person is only eligible to receive NIHB if they are living on a reserve, or formally registered under the Indian Act (73). The relationship between access to NIHB in an urban setting and diabetes was explored in this thesis project, and was significant when the logistic regression model was adjusted for the confounders age and sex (3.48, 95% 1.36-8.87) but a statistically significant association was not found when other confounders were included in the model. The inability to access NIHB off reserves can indicate that not enough government resources are being allocated to help First Nations peoples living off reserves, and as this population is becoming increasingly urbanized,

ensuring First Nations peoples have adequate health coverage off reserves should be made more of a top priority for top government policy makers.

Furthermore, a potential association was found between urban First Nations peoples believing the healthcare services they were receiving were inadequate and diabetes (8.19, 95% 0.97-69.31). The belief that the health services they were accessing were inadequate could be attributed to poor doctor-patient communication between First Nations peoples and doctors they encountered in the healthcare system (74). The level of communication between a doctor and patient can have a significant effect on their relationship and the patient's trust in the health care provider (74). Longer visits with physicians allow for greater patient education and patient participation. For First Nations peoples, a complex history of social and cultural factors may be impacting their health overall as well as their ability to openly share these experiences with a health care provider (69). Towle et al. (75) found that patients who did not have good experiences with their physicians were often more critical of their experience with their health care provider. Taking the time to understand the history of each First Nations person, especially given the complex history of First Nations peoples in Canada, can not only improve a First Nations person's relationship with their doctor; but improve their perception of the healthcare they are receiving as well. Substantial miscommunication and misunderstanding between health care providers and First Nations peoples has been recorded in Canada, the USA and Australia (75). Establishing longer visit times with patients, to not only improve their trust with health care providers but also to enhance the communication between physicians and patients, can improve their understanding and perception of the health care they are receiving. A lack of cultural understanding or

sensitivity can contribute to a lack of trust or feelings of dissatisfaction with the primary health care received (74). Doctors have a duty to spend a reasonable amount of time with each patient to ensure good medical practice. The experience of accessing health services is still largely influenced by the long standing effects of colonization (18), and as such special care should be granted to enhance the experience of First Nations peoples in Canada seeking out medical care.

Saha et al. (76) demonstrate that patients from ethnic and minority groups in the United States tended to be less satisfied with the level of healthcare they received compared with the majority of the population. The lack of satisfaction in the healthcare they were receiving could be directly traced back to a lack of adequate cultural consideration in the patient-physician relationship (76). The belief that the healthcare they are receiving is inadequate could possibly account for the high rate of emergency room visits for this urban population (77). In the Our Health Counts study population, emergency room use was higher for First Nations peoples, compared with the general Hamilton population (37). Of First Nations respondents in the Our Health Counts study, 10.6% reported visiting the emergency room 6 or more times in the previous 2 years, which was significantly higher than then general population of Hamilton, at 1.6% (37). Furthermore, 50% of the urban First Nations population in Hamilton reported at least one visit to the emergency room in the previous year, compared with 22% of the adult population in Ontario (37). A negative perception of primary health care services can compel more people to resort to the emergency room to address their non-emergent health needs. Patients who feel unsatisfied or uncomfortable with their community-based primary care physicians are more likely to use the emergency room for non-emergent

medical issues, as it serves as a back up for patients who feel they are receiving inadequate primary care (18).

Another potential association was found in this urban First Nations population between increased odds of diabetes and the barrier of not being able to locate a doctor (4.07, 95% 0.98-16.84) and not being able to locate health services in the area (7.46, 95% 0.97-57.45). According to the Aboriginal Peoples Survey (2006) the number of off reserve First Nations peoples, and Métis or Inuit individuals who reported seeing a doctor in the past year was significantly lower than their non-Aboriginal counterparts (66). While off reserve First Nations peoples and Métis and Inuit peoples were significantly less likely to talk to a doctor they more were more likely to have spoken with a nurse in the previous year instead. This could in part by explained by the rural location of these populations, where doctor availability is lower (66). In a population based study to examine the prevalence of diabetes among the Métis population in Canada, conducted in collaboration with the Métis Nation of Ontario and the Institute for Clinical Evaluative Sciences (ICES), it was found that Métis peoples living in Ontario who were diagnosed with diabetes were less likely to visit their family physician, compared with the non-Métis population of Ontario (78). Furthermore, Métis individuals in Ontario with diabetes were less likely to receive specialist care from endocrinologists, which is another indicator of lack of access to a primary care physician, as they are often the point of reference to specialized health care services. It should be noted that this study was based on individuals formally registered with the Métis Nation of Ontario, which only represents approximately 20% of the total Métis population in Ontario (78). As individuals diagnosed with diabetes stay healthier and reduce their risk for developing

severe co-morbidities associated with the disease when they maintain regular visits with their doctors to keep their diabetes in check, an emphasis on access to primary care services and better education and preventative programs is needed (78). In this study, diabetes had to be confirmed by a physician, and the fact that a strong association was found between diabetes and the inability to locate a doctor or adequate health services in the area is dangerous, as regular access to adequate treatment plans to prevent the onset of severe co-morbidities associated with diabetes may not be being accessed as much as they should be by individuals with diabetes in this urban population.

Study Limitations

One limitation of this study is the data collected for this study was cross sectional, therefore no causality between health access risk factors and diabetes can be inferred. Because individuals with diabetes may be seeking out medical care more often and are therefore may be more likely to report health access barriers, the directionality of the relationship between reporting a health access barrier and diabetes cannot be inferred. Furthermore, the presence of diabetes had to be confirmed from a health care professional. Because the study population underutilizes health services, the prevalence of diabetes may have been underreported in this population. For the statistical analysis, there is a lack of clear models for regression modeling from data collected through RDS, although currently simulations are being tested for use on this type of data and the PROC GLIMMIX method used in SAS version 9.4 appears robust against Type 1 error rates for this study design. Simulation studies are underway and show that the GLIMMIX method using the statistical software SAS appears robust against Type 1 errors, while the SURVEY procedures may risk an elevated type I error rate. Thus while we are confident

in the conclusions of the GLIMMIX approach, survey methods may be at risk of generating false positives.

Study Implications

This study is one of the first to provide a population based sampling frame for urban First Nations peoples living in Canada. RDS was used to reach this hidden population, providing an asymptotically unbiased representation of urban First Nations peoples living in Canada. Health data on the First Nations peoples living in Canada is scarce, particularly for First Nations peoples living in urban centres, and this study provides unique insight into the association between health access risk factors and diabetes. Findings from this study could support future research efforts that explore the efficacy of more culturally sensitive diabetes prevention and treatment programs, which could be beneficial to curb the rising epidemic of diabetes in this population. As well, these findings could be used to explore the implementation of more adequate health policies to ensure all First Nations peoples living off reserves received adequate health care coverage. Furthermore, the use of multiple logistic regression models to examine the relationship between health access risk factors and diabetes were compared to test for methodological robustness on sample data that was collected through respondent driven sampling (RDS). The appropriate development of linear and logistic regression methods for RDS can assist with future studies that utilize RDS to access hidden populations. In this study the results of regression models using SURVEYLOGISTIC and GLIMMIX in SAS version 9.4 were compared, to assess the relationship between health access risk factors and the diagnosis of diabetes.

Conclusion

The cost of treating Diabetes in Canada will increase from $6.3 billion dollars annually in 2000, to $16.9 billion annually by 2020 (79). Not only does the rising incidence of diabetes have a significant toll on the Canadian health care system, but the development of several co-morbidities as a result of diabetes have a huge effect on the quality of life for individuals with the disease. The Aboriginal peoples of Canada have been identified as a high-risk group for developing diabetes, and greater efforts should be made to curb the rising incidence of diabetes in this population. In accordance with the guidelines established by the Canadian Diabetes Association, individuals at risk for the disease should have their glucose regularly tested and should be informed on the importance of eating healthy, maintaining a healthy weight and getting regular physical activity (78). Greater surveillance on the prevalence of diabetes in this high-risk population is warranted and the development of more longitudinal studies to examine the impact of specific health access variables and how they affect the incidence and prevalence of diabetes in this urban population are needed.

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