Perceived Control over Diabetes Prevention in a Manitoba First Nation Community

by

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A Thesis Submitted to the Faculty of Graduate Studies of

The University of Manitoba

in partial fulfillment of the requirements for the degree of

MASTER OF SCIENCE

Department of Community Health Sciences

Faculty of Medicine

University of Manitoba

Winnipeg

Abstract

Previous research has demonstrated that those who perceive they have high perceptions of control generally have better health outcomes, including diabetes. The purpose of this research was to gain a better understanding of factors associated with perceived control in a Manitoba First Nations community. Data were collected using questionnaires in a community-based participatory research study between June 2011 and February 2012. Logistic regression was utilized to determine factors associated with perceived control over diabetes prevention and the prevention of diabetic complications. Many participants reported they had little or no control over the prevention of diabetes (47.8%) or diabetes complications (42.0%). Factors associated with high perceived control over diabetes prevention included having dyslipidemia, reporting hearing gossip about yourself and experiencing racism. Factors associated with high perceived controllability of preventing complications included having ≥ grade ten education, having dyslipidemia, reporting high chronic stress, and high perceived negative impact from residential school.

Acknowledgements

Many people have helped me throughout this journey. I would like to thank my advisor Dr. Sharon Bruce. I feel truly lucky to have had her as an advisor; her constant support and encouragement was invaluable. I feel that she truly cared, and did her best to provide me with every opportunity she could to ensure that I succeed in life. My committee members Dr. Mignone, Dr. Jiang, Dr. Lavallee, and Dr. Elliott helped me with their constructive comments throughout my degree and their review of my thesis.

I would like to thank members of Sandy Bay First Nation who supported and participated in the study. I truly enjoyed spending time with everyone and I have learnt many things. Thank you to all of our recruiters and community staff, for without you no one would have come to the little brown building across from the Health Centre.

Thank you to all Community Health Sciences students whom I have spent countless hours with in class, lunch, and working on the evenings and weekends. A special thank you to Natalie Riediger (my "twin"); you helped make the car rides and working on the weekend fun. I appreciate you teaching me and lending an ear when I needed someone to talk to.

Thank you Dr. Tate, Theresa Kennedy, Princess Fernandez and Iryna Tsybukh for your help navigating the University of Manitoba's administrative system. I am also grateful for the financial support I received from the Western Regional Centre for Health Services Research (WRTC), the Network Environment for Aboriginal Health Research (NEAHR), the Faculty of Graduate Studies – FGS Special Award, and the CIHR – Regional Partnerships Program Master's Award provided in conjunction with the Manitoba Health Research Council (MHRC).

I would like to thank my family (mom, dad, and Jeremy), for their kindness, patience, and understanding. Dad, I appreciate all the car rides you gave me to and from school. To Terry, thank you for your love and encouragement. Even though completing my M.Sc. in Winnipeg meant that we were physically apart, our almost nightly skype chats, long weekends together, and our hockey date nights (Go Jets Go!) helped me more than you can imagine. I couldn't have made it to this point without you.

For Terry

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Chapter One

Introduction and Study Objectives

1.1 Introduction

The diabetes epidemic among Canadian First Nations populations continues with First Nations (FN) people having a diabetes prevalence 2 to 5 times higher than non-First Nations Canadians (1-5). The prevalence of diabetic complications including cardiovascular disease, renal failure, neuropathy, and retinopathy is also great among FN people (3,5). There are many possible reasons for the significant burden of diabetes and diabetes complications felt by FN peoples. It is known that some individuals have a genetic susceptibility to the development of Type 2 diabetes, as well as lifestyle factors that can both protect or increase one's risk of developing diabetes (e.g., diet and exercise regimens). In Canadian FN communities it can be challenging to meet current healthy lifestyle recommendations to prevent the onset of diabetes or to prevent diabetic complications because of community and social conditions that inhibit access to resources.

Self-care refers to engaging in behaviors that increase chances of preventing diabetes or affecting stable blood glucose management which aids in prevention of diabetic complications. Self-care is one important contributor to positive health outcomes, but adherence to diabetes treatment regimens is challenging and is reported to be low among Aboriginal people (6-9). One crucial factor in self-care is perceived control; those who perceive they have more control in their lives generally have better health outcomes, in part due to health behaviors (10,11). This may be due to the fact that if individuals do not believe their actions can make a difference in preventing diabetes,

they may be less likely to partake in important health promoting behaviors (e.g., healthy diet, exercise, foot checks). For FN peoples an awareness of limited access to resources and social conditions may compromise health by producing an eroding effect on individuals' levels of perceived control (12).

Control can be conceptualized in many ways. For the purpose of this study one's feelings of control will be operationalized as: perceived personal influence over their life in general; perceived personal influence over their health; and perceived personal influence over preventing diabetes (if participant does not have a diagnosis of diabetes prior to participating in the study) or diabetes complications (if the participant has a previous diagnosis of diabetes at the time of study participation).

This project was part of a large community-based participatory research study investigating non-traditional risk factors of diabetes that will be built upon to create a culturally sensitive community intervention aimed at prevention of diabetes and diabetes complications. Given the link between perceived control, disease prevention, self-care behaviors and disease outcomes, a better understanding of perceived control in the community will add to the strength of the intervention. Thus, the purpose of my research is to gain a better understanding of factors that are associated with perceived control and the relationship between perceived control and health and diabetes.

1.2 Objectives & Research Questions

1. To determine the distribution of perceived levels of control over life and physical health.
    a. Do perceived levels of control differ by age, sex or level of education?
    b. Do perceived levels of control differ by level of self-reported stress?

c. Do perceived levels of control differ by chronic disease status?

d. Do perceived levels of control differ by self-rated health?

2. To determine the proportion of individuals who believe they can 'control'/prevent diabetes or diabetes complications.

a. Does level of perceived control over diabetes prevention differ by the burden of diabetes in the family?

3. To determine what factors are related to perceived control over diabetes prevention.

4. To determine what factors are related to perceived control over the prevention of diabetic complications.

As this research is exploratory in nature no a-priori hypotheses were developed for the above mentioned research questions. The limited amount of research that has been conducted in Indigenous communities about control and diabetes has investigated the impact of mastery on health behaviors and/or metabolic control. However, I was unable to find any quantitative research in Canadian First Nation communities investigating structural, community, family, and individual factors and their impact on adults' perceptions of perceived control over health, life, and diabetes prevention (or diabetic complication prevention).

1.3 Ethical Considerations

My M.Sc. research was part of a study on stress and diabetes led by my advisor, completed in partnership with the Sandy Bay Ojibway First Nation. I adhered to the principles of community-based participatory research and I worked with the Community Diabetes Advisory Group, who with my advisor, previously developed a governance

structure for research in the community. I followed the Tri-council Policy Statement on Ethical Conduct for Research Involving Humans (Chapter 9) and the CIHR Guidelines for Health Research Involving Aboriginal People throughout my research project. The larger project received ethical approval from the University of Manitoba Health Research Ethics Board (H2011:171), and approval was also granted for secondary data analysis for my project (H2012:059).

Throughout the study I or one of the other research assistants administered an informed consent to each participant prior to data collection. The purpose of the study, potential risks and benefits of participating, how long data collection would take, and how their confidentially would be protected was explained in a language participants understood. Participants had the opportunity to ask questions prior to informed consent in addition to at any time during the research process. Extra care was taken to conduct the study in an environment built on respect, compassion and dignity.

All questionnaires were de-identified and each participant was assigned an informant number to protect their identities. Electronic and paper-based data are stored in a secure location at the University of Manitoba, and are only accessible to myself, my advisor and other authorized research assistants. Following study dissemination and when there are no secondary uses for the data, they will be destroyed.

Chapter Two

Review of the Literature

This review will first explore the current status of diabetes in Canadian First Nations populations in relation to the prevalence and established risk factors of diabetes and secondary complications. Secondly, it will discuss health care services for First Nations people in Manitoba, with a brief review of historical events that have shaped the current health system. Next, a review of understandings and beliefs about diabetes prevention among Indigenous populations (Canadian First Nations, American Indians, and Australian Aborigines), will be discussed. This will be followed by an overview of the most widely utilized constructs of control, and how these constructs have been applied to research in terms of diabetes management (e.g., glucose levels) once an individual has already been diagnosed with diabetes. Lastly, this chapter will conclude with a discussion of 'control' and how it may influence individuals' beliefs about the prevention of diabetes and diabetes complications in Canadian First Nations communities.

2.1 Diabetes

Diabetes mellitus encompasses a group of disorders that can be divided in to four clinical categories; type 1 diabetes, type 2 diabetes, gestational diabetes mellitus, and other specific types associated with genetic causes or those attributed to medication use (13). This research focuses solely on type 2 diabetes, formerly adult onset diabetes, which is characterized by insulin resistance and insulin insufficiency (13). Type 2 diabetes accounts for over 90% of all diabetes cases among adults in Canada (13).

2.1.1 Diabetes & First Nations Peoples

In Canada, the age-adjusted diabetes prevalence for First Nation adults is 19.7% compared to 5.2% for the general population (14). The high prevalence of diabetes among First Nations people is concerning due to the high proportion of individuals diagnosed before the age of 50. The largest subset of non-Aboriginal people diagnosed with diabetes mellitus in Canada are over the age of 70, while a recent study in Saskatchewan indicates that individuals between the age of 40-49 account for the highest number of incident cases in First Nation communities (1). In addition, diabetes prevalence among First Nation women is greater than among men (15). One in three adults aged 50-59 living on-reserve have diabetes and the average age of diagnosis for First Nation youth with type 2 diabetes is 11 years old (14). In the Dakota Ojibway Tribal Council (DOTC), the age and sex adjusted diabetes treatment prevalence between 1996 and 1999 was 24.9% among adults (16). In Sandy Bay First Nation, a member of the DOTC, type-2 diabetes prevalence in 2003 among adults was estimated to be 29% (3). Risk factors for developing diabetes include obesity, physical inactivity, family history of diabetes, gestational diabetes and stress (4,17).

2.1.2 Complications and Related Co-morbidities

Diabetes complications and co-morbidities contribute to disability, reduced quality of life and increased premature mortality among people with diabetes. Complications of diabetes include heart disease, stroke, renal failure, peripheral neuropathy (ulcers, pain and amputation of lower extremities), autonomic neuropathy (digestive problems, erectile dysfunction) and retinopathy (impaired vision and

blindness) (3,5). Common diabetes co-morbidities include obesity, hypertension, and dyslipidemia (18). The burden of diabetes-related conditions in the study community was high in 2003 when a previous diabetes screening study was performed; 40% of men and 50% of women had two or more chronic diabetes-related conditions (e.g., obesity, dyslipidemia, hypertension). Co-morbidities were found among the youngest adults; 22% of men and 43% of women aged 18-29 had two or more of these preventable conditions (18). Treatment costs for diabetes and diabetes complications among First Nation populations are double that of the general Canadian population due, in part, to the higher rate of admissions to hospitals (19).

2.2 Health Care for First Nations People in Canada

2.2.1 History of Health Care for First Nations People in Canada

In order to fully understand the current organization and financing of health services for First Nations peoples one must understand some of the history of health care in Canada. The 1867 British North America Act outlined the distribution of powers between the federal and provincial governments in the newly established Canada. The Federal government assumed responsibility for "Indians, and lands reserved for the Indians" under Section 91, along with armed forces, the RCMP, new immigrants, and people residing in the territories (20,21). Section 92 of the Act established provincial jurisdiction over health and social welfare services (e.g., asylums and hospitals) (21). In 1904 the Department of Indian Affairs, responsible for Aboriginal communities, appointed a medical director and began to offer medical programs and health facilities (22). The Department of National Health and Welfare was formed in 1945, followed by the formation of the Medical Services Branch (MSB), which took over the Department of

Indian Affairs in 1962 (22). It should be noted that due to how Treaty 6 was written, the Federal government provided medical services to First Nations people as a matter of policy and not law, enabling the Government to alter health services (5). It wasn't until the 1979 *Indian Health Policy* that there was an official health policy for Aboriginal peoples in Canada (22). This policy included provisions for uninsured benefits, including mental health crisis counseling services (23). A major theme in the 1979 Indian Health Policy was the transition of health services to First Nations and Inuit peoples.

First Nations and Inuit Health (FNIH) branch of Health Canada is the current government department responsible for "ensuring the availability and access to health services for FN and Inuit communities; to assist these communities with barriers and disease threats; and build strong partnerships with FN and Unit to improve the health system" (5). FNIH makes formal agreements with First Nation communities, so that the communities take control over their own health programs, and FNIH provides funding to sustain the services and programs (24). Though substantial progress has been made, not all First Nation communities have control over their health programs; Sandy Bay First Nation does have complete control over their health programs. Therefore Sandy Bay is limited in that the community health center can only provide public health programs and not primary care services due to the type of agreement with FNIH. Of note, Sandy Bay was one of the first two communities in Canada to implement the health care transfer of control.

The Federal government funds on-reserve population health programs and non-insured health benefits, while the provincial government delivers primary care and hospital care off reserve. Provinces are required to provide the same general health

coverage and services that they would for any of their provincial citizens. Many First Nations communities have some sort of health care facility, for example a nursing station or health center, on the reserve itself that only serves FN peoples. Funding for FN people who access provincial health care is provided by the federal government by way of per capita monetary transfers called "The Health Canada Transfer" (25). There is an ongoing debate among levels of government about the off-reserve funding for First Nations health services. Provinces argue that the per capita money transfers do not cover "federal citizens" and therefore provinces should be paid extra for services provided to FN people.

2.2.2 Manitoba Specific Services for First Nations People with Diabetes

In Manitoba services to First Nations people on-reserve are provided by the Federal Government and/or the Provincial Government. As of 2011, there were a total of 51 nursing stations, health centers, and health offices controlled by the Federal Government through Health Canada (26). Health Canada also funds two on-reserve hospitals for First Nations people in Manitoba, Norway House Indian Hospital, and Percy E. Moore Hospital (26). Three nursing stations are staffed and managed by Manitoba Health, funded through the Manitoba Government (26).

First Nations people in Canada may also access care for type 2 diabetes from a number of other initiatives such as the ones funded through the Aboriginal Diabetes Initiative (ADI). First established in 1999, the ADI program has been allocated funding until 2015 (27). The primary goal of the ADI is to prevent type 2 diabetes among First Nations peoples, and aims to achieve its goal by funding programs geared at health promotion, primary prevention, screening and treatment services delivered by community

members and other health professionals (27). There is also a limited amount of funding available for community-led research projects. In Manitoba, the Diabetes Integration Project (DIP) is funded through ADI. DIP provides screening services for diabetes and diabetes complications using three mobile teams that serve 19 Manitoba First Nations communities (28). DIP can provide patients with non-emergency and emergency referrals to several different medical professionals in Manitoba.

The University of Manitoba, through the Faculty of Medicine's J. A. Hildes Northern Medical Unit (NMU) also provides care to 17 Manitoba First Nations communities in relation to diabetes including, diabetic foot checkup's, diabetic retinal screening, and a renal health unit in Garden Hill First Nation (29). NMU service does not overlap with the DIP communities (30). Thus, in total, 36 Manitoba First Nations communities receive specialized diabetes care through these two programs.

Unfortunately, the services provided by DIP and the NMU are not continuous in these communities, with drive-in and fly-in visits from nurses, dieticians, and clinicians occurring every few weeks. Also, the clinicians who go to the First Nations communities are not always the same, which may cause a reduced continuity of care. Sandy Bay is not served by either the DIP or the NMU.

2.2.3 Services Available in Sandy Bay Ojibway First Nation

In 1999 a new health facility, the Sandy Bay Health Centre, was constructed in Sandy Bay. The Health Centre delivers community wellness and education services (mental health, family wellness, addictions prevention, health education, and health and

fitness), community health and education services (maternal and child health, communicable disease control, care for individuals with chronic diseases and conditions, environmental health, and access to treatment services), and home and community care (in-home nursing), and primary care provided by itinerant physicians held most weekday afternoons, but is dependent upon physician availability. (31).

As the Health Centre is only able to provide public health programming in the community, Sandy Bay relies on physicians and other health care professionals from outside the community for primary care services. Physicians utilize space in the Sandy Bay Health Centre to set up clinics some weekday afternoons. All physicians come from Portage la Prairie, or Gladstone and see a limited number of patients each day. In 2003, a physician was available in the community for 134 days, which is equivalent to 2.6 days a week (31). The Health Centre also provides space for a pharmacist from Gladstone, who dispenses medications to residents of Sandy Bay every weekday. A retired dentist from Portage la Prairie also visits the community once a month to provide care to residents.

2.3 Indigenous People's Beliefs about Health, Diabetes, & Diabetes Prevention

2.3.1 Health

Due to the epidemic of diabetes among Indigenous peoples, some research has been conducted in relation to individual's beliefs about health and diabetes. Though there are many different groups of Indigenous peoples throughout the world, each with their own customs and beliefs, the experience of colonialism has resulted in some shared life experiences over time. Perhaps as a result of this, similarities have been found in their understandings about health and diabetes. This section focuses on beliefs about diabetes among Canadian, American, and Australian Indigenous peoples.

In Canada Indigenous peoples have described health as a balance of different aspects of life. This belief is often illustrated among FN groups using the Medicine Wheel, where health is achieved through a harmony of mental, emotional, physical, and spiritual well-being (5). Health is not only the absence of disease, to the contrary, one study conducted in a northern Manitoba FN community found that people with diabetes can still perceive themselves as healthy (32). Health is not only viewed as an individual issue, but as a community issue; where community relationships and "wellness" of the community impacts a person's health (32).

2.3.2 Diabetes & Diabetes Prevention

When Australian and Canadian Indigenous peoples have described perceptions of diabetes their understandings are connected to ideas of balance affected by not only individual factors, but also family, community, and societal realities (33-35). For example, among one Canadian FN population, imbalance in one's life, due to changes in the way of life brought on by colonialism, is experienced through separation from traditional land and family members, living a non-traditional life (e.g., alcohol consumption), diet ("white man's food" and lack of wild food consumption), and changes in roles within the family and community. These imbalances are understood to cause changes in sugar levels which in turn contribute to the development of diabetes. (35).

Also connected to diabetes (also referred to as "sugar sickness", "sweet sickness", or "white man's sickness"), can be a belief that western foods that are consumed more often than the past are poison and is one of the causes of diabetes (34). From a FN perspective, diabetes is a new "white man's" disease because it was virtually unheard of

before the 1940's, prior to colonization, which is reflected in the fact that Canadian FN peoples do not have words to describe diabetes in traditional languages, nor do they have traditional medicines specific to diabetes (34,36).

Another common theme expressed in the literature when describing diabetes causation is the belief that diabetes is caused by an external agent or foreign entity in the body which is animate. In one study, First Nations people from a Northern Manitoba Cree community spoke of diabetes as a "he" (35). In another study conducted with the Navajo also indicated that diabetes is considered to be an entity, by the way participants described "doing battle" and "fighting" diabetes with "weapons" (e.g., prayer, traditional or western medicines) (37). Diabetes, "he", can move through the body affecting different organs (e.g., eyes with retinopathy, kidney's requiring dialysis, and limbs causing amputation) (35).

Diabetes is sometimes referred to as 'running in the family'. Diabetes 'runs' in families when multiple individuals across generations have been diagnosed with diabetes. Individuals' perceptions of their family history of diabetes are important because family history can be seen as a risk factor or as protective against the development of diabetes. Risk factors for diabetes are both genetic and environmental, and because genetic traits are similar among families, if blood-relatives have type 2 diabetes the risk of developing type 2 diabetes is increased among other family members. Some studies suggest that family risk of developing diabetes may be divided into different risk profiles: (1) high familial risk: having two or more first degree relatives or one-first degree relative and two second-degree relatives with diabetes, and; (2) moderate familial risk: having one primary relative with diabetes, or two or more secondary relatives with diabetes (38).

Having a negative history of diabetes in families may be considered protective because it may be perceived by individuals that they do not have an increased susceptibility. Conversely, having a family history of diabetes may also be protective in the sense that it could allow individuals who know that they are at increased risk of developing diabetes to engage in protective behaviors (e.g., eating fruits and vegetables, and regularly exercising to maintain a healthy weight).

The theme of diabetes "running in the family" has been described by Canadian, Australian, and American Indigenous peoples alike in their discussions on risk for diabetes (33,34,39). The idea of an illness "running in the family" from a biomedical perspective alludes to hereditary transmission of a disease (39) however, Indigenous communities do not always link diabetes with genetics. For example, in a Manitoba Ojibway community, though individuals discussed the inevitability of developing diabetes by predicting that "everybody on the reserve will be like that", no one described heredity as being the main causal factor (34). In the same study, individuals who did believe that heredity had some influence on the development of diabetes were also more likely to believe that diabetes was brought on by the individual unto themselves. In another study, participants diagnosed with diabetes thought their diagnosis was unexpected even if it 'ran in their family' and often explained their diagnosis because of adverse life events leading up to their diagnosis.

In contrast to the biomedical understandings of diabetes, in which once you have diabetes you always have diabetes, diabetes is not necessarily considered to be a chronic condition among some Indigenous people. For example, some Manitoba Cree participants described diabetes as episodic where individuals can move in and out of having diabetes

based on blood sugar levels (34); "he" can move in and out of the body. In another study that used questionnaires, Tongan participants (n = 72) were more likely than participants of European descent (n = 118) to perceive their diabetes as cyclical in nature where symptoms are acute, and were also more likely to believe that diabetes was caused by "God's will" (40).

2.4 Control

Grounded in the discipline of psychology, the constructs of control and their influence on health have been explored since the 1960's. Control, regardless of how it is defined, has often been found to be a positive predictor of adherence to medications and treatments for many health conditions, healthy behaviors (e.g., following a healthy diet and exercising), and overall mental and physical wellbeing. In the literature however, control is not defined as a single construct. In her review, Ellen Skinner identified over 60 different constructs of control including perceived control (synonymous with primary control), secondary control, locus of control (LOC), self-efficacy, learned helplessness, mastery, self-determination, empowerment, agency beliefs, causal attributions, attribution theory, and fatalism (41). This review will include some of the control constructs most widely applied to health research: LOC; perceived control/secondary control; mastery; and fatalism.

2.4.1Constructs of Control

Locus of Control (LOC)

First described by Rotter in 1966 and further developed and modified by Lefcourt (1981) and Levenson (1973), locus of control is perhaps the most widely used construct

of control (42-44). Locus of control was initially not applied to health, though the general premises and definitions have been often applied to health, economic, and other problems. The basic premise is that individuals' can be considered to have an internal or external locus of control. "Internals" believe they can achieve an outcome by engaging in certain behaviors or actions, while those who are "externals" believe that no matter what they do, the outcome is 'out of their hands' or predetermined by an entity other than themselves (43).

A related construct is Health Locus of Control (HLOC), which has been applied to study treatment adherence and disease outcomes for individuals with diabetes, HIV, kidney disease, mental illness, and various types of cancers (45-49). Wallston and colleagues (1976) were the first to develop an HLOC scale, with several variations being later developed with disease specific subscales, including a Locus of Diabetes Control (LDC) subscale in the Multidimensional Health Locus of Control Scale (50). Using the HLOC scale, individuals who score high are called "health-externals" and believe that they have little control over their own health. Instead, their health outcome is believed to be determined by luck, chance, and/or other factors (51). Conversely, individuals who score low are considered to be "health-internals", meaning that they believe that they can exert influence on their own health outcomes (51).

Perceived (Primary) Control & Secondary Control

There has also been research on perceived control; in one sense perceived control is considered to be whatever the individual being studied considers "control" to be (52). Perceived control is sometimes used synonymously with primary control, and describes

individuals' beliefs in their abilities to directly influence their environment in some form (53). Primary control is closely linked with Locus of Control and learned helplessness, as these constructs also emphasize belief in one's ability to change their own environment. An example of primary control in a diabetes context is when people believe that they can prevent themselves from developing diabetes by eating healthy and exercising, thus exerting primary control.

Primary control was first described by Rothbaum and colleagues (1982) as a two-process model in which an individual could simultaneously experience both primary and secondary control (53). Secondary control occurs when one "brings themselves into line with environmental forces"; in other words, when an individual changes their beliefs or interpretations of a specific event to make sense of and adapt to their reality. Secondary control contrasts with the construct of learned helplessness in that helplessness is when individuals cease trying to effect change because they believe nothing they do will have an impact (i.e., they relinquish control) (54). Learned helplessness is often due to a prolonged history of life experiences where they are continually unable to control aspects of their lives (41). Rothbaum and colleagues describe that rather than being "helpless or hopeless" individuals exerting secondary control are adjusting to their environments rather than relinquishing control altogether as was previously thought (55). For example, individuals saying they could not prevent diabetes because of the unavailability of resources such as healthy foods, primary care, medications, opportunities for physical activity, are demonstrating secondary control.

Rothbaum and colleagues suggested that at least four sub-categories of secondary control exist including: predictive, illusory, vicarious, and interpretive control. Predictive

control can be defined as knowing that negative events are coming up and psychologically preparing for them so as not to be disappointed. The negative experience is seen as inevitable; for example, a person who exerts predictive control may rationalize the development of diabetes as unavoidable so they are not disappointed if they are diagnosed with diabetes at a later time. Illusory control is a belief that events occur because of luck, fate, or chance, which is very similar to "externals" in the LOC theory. Religious beliefs or beliefs in Mother Nature also fall into this category of secondary control. For example, a person may believe that diabetes is "meant to be" regardless of what they do because of a higher power. Vicarious control is the belief that a powerful other can and will help you. For example, a person who has diabetes puts trust in their physician, and believes that the physician will come up with a plan to 'fix or control' their diabetes. On the other hand, interpretive control is seeing the bright side of things. For example, positively reinterpreting having diabetes as beneficial because it provides an opportunity to make life changes and influence their family, or receiving more social assistance money enabling the purchase of better quality or greater quantity of food.

In a competing model, Jutta Heckhausen and Richard Schultz (1995) postulate that a person turns to secondary control only when initial attempts to gain primary control have failed, or the person is not in an environment where primary control can be attained (56). According to Heckhausen and Schulz, secondary control helps individuals cope with negative events throughout their lives (56), though researchers postulate that the Rothbaum concept of control also achieves this. The Heckhausen and Schulz theory of control is referred to as the life-span theory of control.

Thus in current research about primary and secondary control, a division lies between researchers who debate the temporal and functional relationship between the two constructs (i.e., whether secondary control occurs simultaneously with primary control or, if secondary control occurs only after attempts at primary control are relinquished). Researchers who focus solely on secondary control can be loosely grouped in to two main research domains; (1) secondary control as a disposition (i.e., personality trait), and (2) secondary control as a coping strategy to deal with stressful life events including illness.

Of importance in the current research study are cultural influences on control. It is more typical of western societies to place emphasis on self, or independence, and research suggests individuals from western countries are more likely to express primary control (57,58). Conversely, non-western societies such as Japan, and Canadian First Nations communities, place a larger emphasis on interdependence. This is exemplified in Canadian First Nations communities where an individual is connected to both the community and ancestral land. In situations where more emphasis is placed on interdependence people may be more likely to have a higher degree of secondary control (58). Communal mastery has been used to describe this type of secondary control. In one study, Native American women described that they could overcome problems by working together as a community (i.e., communal mastery), instead of only relying on themselves (57). The authors of a study among lesbian, bisexual, and two-spirited American Indian and Alaskan Native women also suggest that mastery among Indigenous communities may take into account "mobilizing familial, social, cultural, psychological, and spiritual resources that diminish the impact of a stressor"(59). These authors further provide an

example of how for some North American Tribes "exercising individual agency is an ancestral mandate" where the behaviors of individuals in the present affect subsequent generations (59,60).

Fatalism

The concept of fatalism was originally closely linked to Locus of Control. Similar to external locus of control, fatalistic individuals were defined as those who believed that they could not affect their future; that their fate was out of their hands (61). It was not until the 1990's that fatalism was applied to the field of health beliefs and behaviors. Fatalism is a belief that events are predetermined and individuals do not have the ability to change them (62). Fatalism can be used to confront uncertainty regarding the future, to reduce stress, or to address perceived consequences of behavior (63). Fatalism occurs on a continuum and is not "irrational"; people who are deemed to have fatalistic behaviors behave rationally based on their beliefs and assumptions (64). For example, women who avoid breast screening exams may have legitimate reasons to avoid screening based on social and cultural meanings attached to illness, beliefs about etiology of the disease, bio-medical beliefs and personal barriers (64).

Self-Efficacy

Self-efficacy is an integral concept within Social Cognitive Theory (SCT) (65). Though definitions may vary, generally self-efficacy is defined as the belief that one can successfully complete a task required to produce a given outcome (66). Self-efficacy centers on control or ability to affect adverse events. The theory posits that individuals

who perceive that they are able to exert control over a situation are less likely to feel fearful, overwhelmed, and are more likely to succeed at the given task (67).

Mastery

In relation to diabetes, empowerment and mastery are often closely related in the literature. With chronic disease, empowerment occurs when an individual feels that they are capable of doing something positive to improve or gain control of disease (68), whereas mastery is when individuals believe that they are capable of overcoming barriers on their own (69). Mastery is different from perceived control because mastery focuses on repetition or practice to master something in order to change an outcome. For example, someone with diabetes can master reading blood sugar levels and knowing when to give themselves insulin through repetition, thus enabling them to achieve glucose control (the outcome).

The most commonly used mastery scale is the Pearlin and Schooler scale which was developed in 1978 (70). The scale has 7 questions on a 5-point likert scale. Questions included in the scale are as follows: (1) I have little control over the things that happen to me; (2) there is really no way I can solve some of the problems I have; (3) There is little I can do to change many of the important things in my life; (4) I often feel helpless in dealing with the problems of life; (5) Sometimes I feel that I'm being pushed around in life; (6) What happens to me in the future mostly depends on me; and (7) I can do just about anything I really set my mind to. Questions in this scale are general, and are a measure of global mastery and are not specific to beliefs about the control over health or diabetes.

2.4.2 Control, Prevention of Diabetes Complications & the General Population

Though individuals who have a high internal locus of control are hypothesized to have better diabetes outcomes (e.g., better metabolic control, and lower co-morbidities), results from studies are often mixed suggesting a complex relationship between metabolic control and locus of control. Other factors that may influence the relationship include: perceptions of health, perception of risk, racism, autonomy, treatment adherence, self-efficacy, depression, patient-provider relationship, age, family support, stress, and coping style (see appendix for a listing of related research) (11,71-77).

In a study among low-income individuals with type 2 diabetes, control, as measured by the Multidimensional Health Locus of Control (MHLC) scale, was statistically significantly related to medical regimen adherence as measured by HbA1c level (45). The research however did not take into account self-reported behaviors. Through their research the authors also concluded that different 'types' of control (Chance HLOC, Internal HLOC, God HLOC, Other People HLOC) may interact differently with glycemic control, causing some of the mixed results shown in previous studies (45).

In another study, Bailis and colleagues (2001) hypothesized that perception of control over life events may influence differences between health among socioeconomic classes (77). Data for their study were obtained from the National Population Health Survey of Canada, and using various modeling techniques they found evidence to support their theory that perceived control is positively related to socioeconomic status (i.e., those with high-SES tended to have greater perceived control). Conversely they did not find that the effect of perceived control on health outcomes was mediated by health behaviors

(e.g.. alcohol consumption, smoking, blood pressure examinations, and leisure physical activity). In their conclusion one of their recommendations was the need to develop psychosocial interventions to increase individual's perceptions of control.

Another longitudinal study conducted with 124 patients of a health-promotion facility in Winnipeg that specializes in health-education, cardiac and physical rehabilitation, investigated the relationship between control beliefs, relative autonomy, and age. Using the multidimensional HLOC scale to measure level of control, and the "Treatment Self-Regulation Questionnaire" to measure relative autonomy they found that HLC beliefs changed with age. In addition they found that a lack of relative autonomy toward health related goals, as measured by a lower score on the "Treatment Self-Regulation Questionnaire", seemed to influence patients' fatalistic attitudes about disease which they hypothesized may affect how they cope with stressful health events (72).

Several studies have identified a relationship between self-efficacy, depression, diabetes outcomes, diabetes self-care behaviours, and diabetes related co-morbidities (78-80). It is hypothesized that individuals who have high self-efficacy, are more likely to partake in healthy behaviors, such as physical activity (81), therefore increasing the likelihood of better disease outcomes. As with studies investigating the impact of one's Locus of Control tendencies on diabetes outcomes, the relationship is not linear, nor is it simple. However, unlike Locus of Control, studies on the impact of self-efficacy on diabetes have shown more consistent results with those who have high self-efficacy having better outcomes than those in similar situations who have low self-efficacy (80).

A study by Cherrington and colleagues among individuals with Type 2 diabetes attending one of two primary care clinics (Vanderbilt University Medical Center, and

University of North Carolina School of Medicine) investigated the relationship between glycemic control, depression, and self-efficacy. Glycemic control was assessed by HbA1c level ascertained from chart reviews in the 6 months prior to the study, depression was assessed using the Center for Epidemiologic Studies Depression (CES-D) Scale, and perceived self-efficacy was measured using the Perceived Diabetes Self-Management Scale (PDSMS), where higher scores indicate higher perceived self-efficacy. In this study the authors found that self-efficacy mediates the relationship between glycemic control and depressive symptoms in men, but not women (82). High self-efficacy has also been found to be protective against poor health outcomes for people with diabetes in relation to walking ability and cardiovascular disease complications (79). Several research studies have provided evidence to support including self-efficacy enhancing components to any intervention to reduce disability caused by chronic disease (for a review see (80)).

The majority of research in the field of health fatalism has focused on colorectal and breast cancer screening behavior, and HIV/AIDS prevention and testing (83-86). However, there is a growing literature on fatalism and diabetes. A general trend of the research is that fatalistic attitudes in relation to diabetes onset and progression are associated with poor self-care behaviors, such as non-adherence to treatment. Further, fatalistic attitudes have been found to be associated with poor glycemic control and lower self-rated overall quality of life (62,87,88). For example, adult patients with type 2 diabetes using primary care clinics in an academic medical center in South-eastern U.S. (n = 216) who had diabetes fatalism, operationalized as a higher score on the Diabetes Fatalism Scale (DFS scale), had higher HbA1c levels (i.e., poorer glycemic control), poor self-care adherence (measured by a 23-item Diabetes Knowledge Test) and a lower

quality of life (e.g., more depressed, as measured by the Epidemiological Studies Depression scale) compared to those who were not fatalistic (88).

Often, a family history of chronic disease can influence fatalistic thoughts, as the individuals may think that their illness outcome is inevitable. Due to a sense of "inevitability", the individual may not believe that the illness is preventable or can be successfully managed, and therefore may be less likely to adhere to treatments (9,89). In a study of people with people who had a positive family history of diabetes (n = 118), it was investigated if communicating risk factor information to individuals would impact their behavioral intentions (e.g., eat healthy, and engage in physical activity), worry of developing diabetes, or personal control and fatalism. Individuals were split into two equal groups: one was given information specific to family risk factors while the other group was given information about general risk factors for diabetes. Those who received personalized familial risk information had a higher perceived personal control, which the authors interpreted as not being fatalistic, over diabetes prevention after three months compared to those who did not receive personalized risk information. However, neither group had any intention improve behavioral intentions compared to baseline measurements.

Though perceived control has often been found to be an important predictor of positive health outcomes there is also research suggesting an inverse relationship between health and sense of control (i.e., those with high perceived control sometimes have worse health outcomes). Thus, it may be an over-simplification to assume that a high level of perceived control can produce better outcomes itself. For example, a study of adults with type 2 diabetes (n = 123) who also had a family history of diabetes found

that those with a high belief in diabetes controllability were less adherent to their medication (pill use) regimen, as measured by a self-report survey (90). To try and explain why some studies indicate that high levels of control may be detrimental to health, Evans and colleagues developed a theory about "dysfunctional control mismatches" (91). The theory postulates that when there are mismatches between ones environment (e.g., living in a place where there is opportunity to exert control, vs. living in a place where you can exert little or no control), and behavior cognition (e.g., whether you are actually capable of achieving an outcome), and/or control desires (e.g., whether you actually want to control), and/or control cognitions (e.g., whether you think it would be possible for others to achieve a goal, vs. your own ability to achieve the goal), negative effects (e.g., negative emotions, poor task performance, stress) can result (53,91). In other words, if an individual wants/likes control, but is in an environment where they are unable to exert control, it could result in the development of negative emotions.

2.4.3 Control, Prevention of Diabetes & Indigenous Populations

Thompson and Gifford (2002) completed a three-phase research project, combining ethnographic and quantitative methods, among Aborigine elders living in Melbourne, Australia to investigate how beliefs about behavioral risk factors for developing Type 2 diabetes may be utilized to construct a more culturally meaningful epidemiological risk factor survey instrument (33). Of interest, participants rarely spoke of what would happen to their diabetes in the future, and few engaged in forward planning. The authors attributed this lack of forward planning to the fact that Melbourne

Aborigines identified that they "have little control over the future" (33). Similarly, in a separate ethnographic study among the Dine (also known as Navajo), n = 20 interviews of adults with diabetes, the authors concluded that a feeling of little control over their future may be linked to feelings of powerlessness already experienced by having little control over social changes and a perceived domination by westerners since colonization; they may feel "powerless against the system" (37).

A feeling of a lack of control may influence individuals' abilities to engage in behaviors that protect against the progression of diabetes toward the development of diabetic complications. This is exemplified in a study among the Gila River Indian community where obese normoglycemic participants (n = 44) did not believe that diabetes was preventable based on life experiences with diabetes in their community (92). The authors also reported that 82% (36/44) of participants thought diabetes was uncontrollable once diagnosed, many thought that engaging in behaviors to prevent onset of complications would be futile, and 91% thought they would eventually get diabetes (92). Some participants even described prevention of diabetes as a "waste of time and effort". The author in this study went on to describe feeling a lack of control as "surrender", and not "learned helplessness" because "surrender" also refers to the impact of historical processes. Specifically, "surrender" was the feeling participants described related to their perceived inability to control things they believed to be inevitable. In another study specific to American Indian women, a major theme regarding onset of diabetes was fatalism and inevitability (93). A perception of inevitability was described as knowing it was going to happen, often because diabetes was common in their families.

In one ethnographic study, participants (n = 14, 11 with diabetes and 3 without diabetes) from a remote Australian Aboriginal community were interviewed to explore beliefs about diabetes and what would be important for participants if a diabetes health education program was created (36). Most participants with diabetes partook in biomedical treatments (e.g., taking medication they had been prescribed), though few said they believed that the treatments would have a positive effect, and no participant identified exercise or weight loss as part of a diabetes treatment regimen (36).

Quantitative research on perceived control and health outcomes has been conducted with few Indigenous communities. Daniel and colleagues investigated diabetes prevalence, behavioural and anthropometric risk factors, and psychosocial constructs, including mastery, in three First Nations communities in British Columbia (94). The study included non-pregnant adults who had diabetes or those at risk for diabetes (i.e., had primary or secondary blood relatives with diabetes), leaving a final sample of 189. Control was measured using a 7-item, 5-point Likert-like mastery scale. The authors' found that low levels of perceived control were inversely associated with fasting glucose levels in these communities; those who scored higher on the mastery scale had lower glucose levels (e.g., no diabetes, or better control of diabetes) (94). Another study conducted in Australia, found that having higher control, defined as having a higher score on the mastery scale, among adults over 25 years was associated with higher levels of physical activity and greater vegetable consumption, and that individuals who had greater control had lower perceived and chronic stress (95). The authors also found that for both sexes, mastery was inversely related to age, and that for participants younger than 25 years old, women scored higher on the mastery instrument, and therefore perceived

themselves to have greater control than men (95). This study employed questionnaires, and had a total of 177 participants.

In 2009 The Strong Heart Study published information about American Indian perceptions of control, measured with the multidimensional HLOC, and its associations with anthropometric and demographic characteristics. Three study sites were included, with a total of 3601 participants (96). Most individuals who participated scored the highest on internal control, meaning that the majority of individuals thought that they themselves could affect their health. Women had higher Chance HLOC beliefs than men (96). Older individuals had higher scores on Powerful Others scales, and lower Internal HLC scores. The more highly educated the participants, the less individuals' thought that their health was due to chance. (96) Among men, those who were overweight or obese had higher Internal HLC scores compared with normal weight men. For women only, waist-to-hip ratio was positively correlated with higher beliefs in powerful others (96). This was likely the first study investigating multidimensional HLOC in an American Indian population.

A report on the 2008/10 First Nations Regional Health Survey (RHS) was just released in June 2012 and also included information about mastery among First Nations people (97). They found that mastery scores using the Pearlin and Schooler mastery scale were similar to that of the general Canadian population, though they did not specify the exact mean values. They found that those with more than a high school education had higher perceptions of control compared to those who had an education of grade 12 or less. They also found that those with low or moderate psychological distress measured by

a score of 19 or less out of 40 on the Kessler Psychological Distress Scale, was positively associated with greater mastery scores (97).

2.4.4 Control, Stress & Illness

Stress is a complex notion that can be defined in several different ways. In keeping with the larger study, stress is defined as "a state of imbalance or threatened homeostasis" (98). Stressors are objective events that occur in an individual's life that have the potential to alter one's homeostasis. The history of marginalization of Aboriginal peoples in Canada has resulted in significant levels of personal and community stress (99).

It is known that humans have adapted to acute stress by developing a set of physiological responses commonly known as the "flight or fight" response (100). However, when stress becomes chronic, physiological responses to stress can have long-term health consequences (101,102). Research has linked chronic stress to the onset of diabetes through two main stress systems. The HPA axis helps control the release of cortisol, and the sympathetic nervous systems controls the release of chatecholamines. These stress hormones cause rapid breakdown of glycogen stores in the liver converting them to glucose and also results in insulin resistance (100,102). Psychosocial stress has been shown to double individuals risk for developing diabetes (103). The stress response is also associated with inflammatory processes that are implicated in cardiometabolic diseases (104). Overall, chronic stress experienced by Canadian Aboriginal populations predisposes them to acquiring diabetes and other chronic illnesses (102). One's ability to cope with stressful events may be related to one's risk of developing diabetes. However, the relationship between stress and diabetes is complex, with some researchers proposing

that psychosocial factors, such as perceived control, may moderate stress' influence on health, including mental health (105). Authors of the book *"Personal control in social and life course contexts"* identified the lack of research focusing on the relationship between different types of stress (e.g., life events, chronic stressors, and traumatic events) on control as a gap in the literature (105).

2.4.5 Control Questions Used in This Study

The control questions used in this study are those of primary/perceived control thus in one sense allowing the participants to decide what "control" is to them when answering the survey questions. Many of the constructs outlined in this are used in research to test a particular aspect of control (e.g., sense of empowerment, helplessness, ability to overcome barriers). Due to the paucity of research about control and chronic disease in First Nations population it was decided that no predetermined construct of control would be tested in this research. Instead, this research is exploratory in nature, and investigates what factors may be related to control over health, life, and diabetes prevention (or diabetic complication prevention) in Sandy Bay Ojibway First Nation.

2.5 Summary & Relevance to Research

Although several studies have investigated the link between control and health outcomes, there is a lack of information for Canadian First Nation communities in relation to control and diabetes. In addition, most of the studies that have been conducted have not investigated what influences levels of perceived control over life, health and diabetes prevention in First Nation communities, nor have the existing studies had large sample sizes. The one study that did investigate associations between control,

demographic and anthropometric measures utilized the multidimensional HLOC which may be difficult to measure during a clinical encounter. The research and theories discussed have demonstrated that the relationships between control and health are complex.

Research with non-Indigenous peoples may be relevant to First Nations communities. For example, research about autonomy and control may have relevance to First Nation residents given the relationship between communities and the Federal government for the provision of health care services. In addition, relationships between control and SES, where it was found that those with high-SES tended to have greater perceived control, may be very relevant as it may help in part explain the low health status among FN people in Sandy Bay due to their relatively low SES compared with other Canadians.

Likewise, it is important to explore beliefs about causation and disease progression because they may have an effect upon one's perceptions of control, and likelihood to develop diabetes or diabetes complications. Individuals' feelings of low control may not be that they are "giving up", but reflect their lived experiences, and how they interpret and rationalize the impact of diabetes on themselves and their community. Because of this it may also be important, due to the high prevalence of diabetes within communities, to take into account family history of diabetes when attempting to explain any relationship between perceived control and diabetes. In addition, given previous research it is plausible that for individuals who live in a community such as Sandy Bay, where their environment is such that there are few opportunities to exert control (e.g., few job opportunities, external policies that limit choice), it may be adaptive (e.g., to reduce

stress) to have less desire for control, or not try to achieve a goal at all (e.g., fail to engage in exercise or eat healthy to prevent diabetes). It is also therefore important to include measures of stress to investigate relationships between control and health.

Chapter 3

Methods

3.1 Conceptual Framework

The conceptual framework utilized in the study was designed to fit within the Sandy Bay context and is based on work by Mark Daniel and colleagues that theorizes relationships between environmental risk conditions and cardiometabolic diseases (106,107). Environmental risk conditions in this sense are "subjective or objective properties of social, built, or physical environments" that may increase individual's chances of developing certain diseases when exposed to the conditions (106). Daniel's work was chosen as a basis to this conceptual framework because it was developed in an Indigenous worldview along with epidemiological data, and incorporates psychosocial factors such as perceived control. The framework is also designed to enable the investigation of risk for the development of diabetes at a neighborhood (or community) level, while taking into account individual data (106). This is something that has occurred extensively in non-Indigenous populations, but has rarely been investigated among Canadian First Nations communities (106).

As with Indigenous perspectives of health and diabetes, the conceptual framework is multifaceted with factors that operate at different levels continually interacting with each other. Broadly, the conceptual framework is divided into two main components that affect cardiovascular disease and diabetes: environment and individual. Environment is made up of factors that operate at the structural, community and family level. Examples given in Daniel's framework include food security (or insecurity), poverty, and the presence of a residential school that operate at the community level, and affect individual

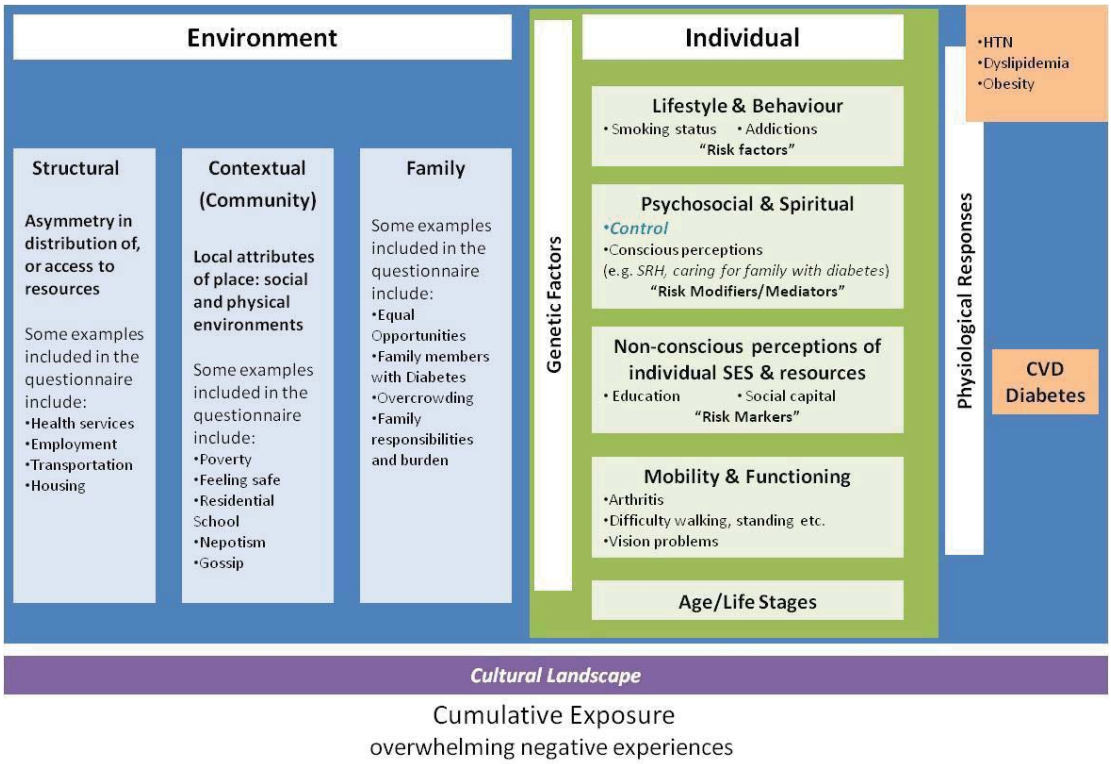
health (108). The conceptual framework includes (**figure 3.1**) brief descriptions and examples of environmental features included in the First Nations Community-Based Stress and Coping Survey© to increase clarity.

The second main component of the framework is at the individual level which includes lifestyle and behavioral, psychosocial and spiritual, non-conscious perceptions of individual SES and resources, mobility and functioning, and age/lifestyle stages. While individual factors are felt or acted upon by the individuals, they are closely tied to and affected by the environment in which the individual lives. In the frameworks developed by Daniel and colleagues, control, and mental health are considered to be risk modifiers or mediators in the relationship between some environmental and disease outcomes. Psychosocial factors (e.g., perceived control, depression) may be key to understanding cardiovascular disease risk, because disease etiology is only partially explained by taking into account behavior (94,109). Though stressors are felt individually, many operate at a level external to the individual and were thus placed in the environment section of the framework. In addition, "stress" was not specifically included in the environment or individual categories of the framework, because all of the events or situations listed in those sections can be negative or positive and can therefore be stressors themselves. Genetic factors and physiological responses are also included in the framework, though they are not investigated in this research project.

At the bottom of the figure "cultural landscape" is also included. The inclusion of cultural landscape encompasses traditional practices, traditional beliefs, and the Indigenous connection to land that is in itself affected by the historical trauma experienced by Canadian First Nations people that are passed on through generations

(110). So many of the factors at the environmental and individual levels are intertwined with historical trauma, and the subsequent changes experienced in the cultural landscape have, for example, influenced social pathologies and risk behaviors for cardiovascular disease (e.g., substance abuse, violence) (110-112). Culture is also important, because in some instances it is thought to reduce or limit the impact of negative environmental conditions on disease development. The cumulative exposure of the negative factors included in the framework may cause an individual to move toward the development of cardiovascular disease, diabetes, and co-morbidities (hypertension, obesity, dyslipidemia).

Figure 3.1 Theoretical framework



3.2 Design

This study employed a population-based quantitative cross-sectional research design. The research is part of a larger continuing project on stress and diabetes in Sandy Bay First Nation. Data for this study were collected between July 2011 and February, 2012. As this research was completed in partnership with a First Nation community, the principles of Community-Based Participatory Research were employed in all aspects of study design, data collection, analysis, and dissemination. The governance structure for the project was the Sandy Bay Community Diabetes Advisory Group.

3.3 Study Community Description

The Sandy Bay Ojibway First Nation (SBFN) is located approximately 200km from Winnipeg on the western shore of Lake Manitoba. In 2011, the total registered population of Sandy Bay First Nation was 5679 (on and off-reserve), with approximately 80% of the population speaking Ojibway (113). The community has its own Health Centre, Child and Family Services agency, sports arena, school, and volunteer Fire Department. In a 2003 study, it was determined that 70% of adults in the community were unemployed (3). The burden of diabetes and diabetes related co-morbidities in Sandy Bay First Nation is great with a diabetes prevalence of 29% in 2003 (3). Also in 2003, 40% of men and 50% of women had two or more chronic conditions (18).

3.4 Participants

Eligible participants were adult (18+) registered members of Sandy Bay Ojibway First Nation (SBFN), or registered First Nation individuals who have been long-term residents of SBFN. Participants must also be non-pregnant. Using these criteria, the total eligible population for the larger study was estimated to be approximately 1400. Data

used in this study included individuals who participated in the study between July 2011 and February 2012.

3.5 Survey Instrument & Origin of Variables Used

Two survey instruments were employed in the present study; the "Demographic and Health Status Questionnaire", and the "First Nations Community-Based Stress and Coping Survey©" (aka: Stress and Coping Survey). The "First Nations Community-Based Stress and Coping Survey©" was developed by my advisor, Sharon Bruce, and underwent a pilot study in 2007 where a total of 175 community members participated. The instrument was developed with the Community Diabetes Advisory Group of the Sandy Bay Ojibway First Nation using pre-existing scales as templates. These pre-existing instruments include, the Canadian Community Health Survey Cycle 2.1 (114) for questions on coping, Cohen's Perceived Stress Scale (115), Survey of Recent Life Experiences Scale (116), perceived control questions developed by Chipperfield, Campbell, and Perry (117), and the Social Capital Individual Questionnaire (118,119).

3.6 Measures

A table detailing how variables were coded, and what questions were utilized to create the variables are included in **table A** in the appendix.

Demographic Variables:

Age was calculated based on each participant's self-reported date of birth, and the day that they completed study protocol. Age was used at different points as both a continuous variable and as a categorical variable (18-24, 25-34, 35-49, and 50+). *Marital*

status was self-reported, and responses were grouped into two categories: not married, and married. Several individuals (n = 66) did not specify their marital status. Using criteria based on responses from five questions in the Stress and Coping Survey, 47 individuals were assigned a marital status of not married, or married. If respondents answered "Not Applicable" to "now or in the past have you ever had major conflicts of arguments with your spouse/partner?" (question 9), "now or in the part has your spouse/partner ever had a drinking problem" (question 25), "now or in the past has your spouse/partner ever had a gambling problem?" (question 26), "now or in the past has your spouse/partner ever had a problem with drugs?" (question 27), or "if you have a spouse/partner, how often do you talk to him/her to deal with stress?" (question 80) they were assigned to the not married group. If the participant said that they were currently experiencing question 9, 25, 26, or 27 they were considered to be currently in a relationship and they were assigned to the married group. Based on the above criteria, 9 of the 66 non-response items were assigned to the not married group, and 38 were assigned to the married group. *Level of education* was also self-reported. In keeping with previous studies in Sandy Bay the median level of education was used to create two categories for level of education, less than grade 9 and ≥grade 10. Because few participants responded "prefer not to answer" for education level (n = 10), these individuals were not included in analyses that included this variable. *Sex* was self-reported and categorized as male or female. *Fluency in an Aboriginal language* was assessed by a single self-report question with three response categories. Individuals who said that they can understand it but not speak an Aboriginal language were grouped in to one category with those who could not speak or understand it. Thus, creating a

dichotomous variable: fluent vs. not fluent. *Current employment status* was also assessed with a single question asking if they currently worked for pay. Each participant provided a response of yes or no for this question.

Health and Disease Variables:

Venous blood samples after a 12-hour fast were taken for each participant by a nurse, processed and stored on-site at -20°C. Samples were transported frozen from Sandy Bay to the Clinical Chemistry Laboratory at the Health Sciences Centre for analysis. *Diabetes* was defined as fasting blood glucose of ≥7mmol/L, or self-reported previous diagnosis of diabetes by a health care professional. Participants with a fasting glucose value between 6.1 and 6.9mmol/L are considered to have Impaired Fasting Glucose (IFG). *Dyslipidemia* was defined as a HDL-cholesterol value ≤1.03 mmol/L for men and ≤1.30 mmol/L for women, and a triglyceride value of >1.7mmol/L (120).

Body Mass Index (BMI) was calculated for each participant [BMI = Weight (kg)/Height (m) x (Height (m)], and used as a continuous variable. *Obesity* was assessed as a binary variable, where obesity was defined as a BMI ≥30 kg/m^2. *Abdominal Obesity* was defined as waist circumference >88 cm for women and a waist circumference > 102 cm for men.

Chronic disease status was determined for each individual utilizing several different biomarkers, and self-report answers from the Demographic and Health Status Questionnaire. *Mobility* issues were determined by a composite variable from questions related to difficulty walking 350m, difficulty going up stairs (12 or more), difficulty standing for 20 minutes, and difficulty walking from one room to another on the same

floor. The scores for the four questions (0 = No, 1 = Yes), were totaled giving a final score between 0 and 4, with a higher number indicating a greater degree of mobility difficulties. Vision problems were assessed similarly to mobility issues, as the scores on two questions, difficulty seeing the words on a page and someone's face across a room, were added (0 = No, 1 = Yes), were totaled giving a final score between 0 and 4. *Hypertension* for people without diabetes was defined as a systolic pressure > 140mmHg or a diastolic pressure > 90 mmHg, or a previous diagnosis that was self-reported. For individuals with diabetes, hypertension was defined as a systolic pressure >130mmHg or a diastolic pressure >90mmHg. *The number of chronic conditions* variable was derived by adding up the number of conditions that the participant self-reported or was measured during the study, these conditions included: diabetes, heart disease (self-report), hypertension, obesity, arthritis (self-report), and dyslipidemia. Because few people had four or five chronic conditions, those who had three, four or five chronic conditions were combined in to one category. The presence of *co-morbidities* was assessed for individuals who self-reported a diagnosis of diabetes at the time of study completion. A dichotomous variable was created: 0 = no co-morbidities, 1 = at least one co-morbidity (one or more of: dyslipidemia, HTN, or abdominal obesity). *Self-rated health (SRH)* was assessed using a single question where individuals rate their health on a 5-point Likert scale compared to other individuals their age. *Smoking status* was assessed by two self-report questions asking participants if they ever smoked or currently smoke cigarettes. Packyears was calculated [Number of cigarette packs smoked per day / number of years smoked], where one pack equaled 25 cigarettes.

Control and Stress Variables:

Perceived levels of control were determined using four different variables; perceived control over health, perceived control over emotions, perceived control over life in general, and perceived control over diabetes prevention (or prevention of diabetic complications if they had a previous diagnosis of diabetes). When the diabetes prevention question was asked by the research assistant, it was tailored to the participants' diabetes status. If the participant did not have diabetes, he or she was asked: "How much personal influence do you feel you have over preventing diabetes?", and if he or she indicated that they were previously diagnosed with diabetes the question was: "How much personal influence do you feel you have over preventing diabetic complications?". Three of the four control questions (control over emotions, physical health, and life in general) were developed by Chipperfield for use with elderly populations and were piloted in a previous study in the community between 2007 and 2008 (117,121) The control question about diabetes prevention was developed for the 2011/2012 stress study in the same style as the other questions. For each measure of control the four responses (none, a little bit, quite a bit, and a lot) were collapsed into two categories: (1) low control, which included responses none and a little bit; and (2) high control, which included responses quite a bit and a lot. *Perceived influence over improving the community* was assessed by a single question "Now or in the past have you believed that you have some influence in making the community a better place to live?".

Perceived chronic stress was assessed by a single question asking about the stress participants experienced over their entire lives and collapsing response variables into two categories as was done for the perceived control questions. To determine level of

perceived acute stress five responses from the questionnaire were summed for each individual giving a score between 5 and 25, with higher scores indicating more perceived acute stress. Individuals whose scores were below 13 were grouped into one variable called low stress, and those who scored 13 or higher were considered to have greater acute stress. A score of 13 was used to create the dichotomous variable because it was the median response, and individuals who had less than a score of 13 did not have any high stress responses to any of the five questions utilized to develop the composite variable. Questions about *negative events in one's life* (stressors) were assessed using several questions, with multiple response categories. Responses were grouped in to four groups: acute, chronic, historical, and no/never. Acute stress was defined as the event only happening in the last month. Chronic stressors were events that occurred over the last year, or in multiple response categories (e.g., now and over the last year, over the last year and in the past, now and over the last year and in the past). Historical stressors only occurred in the past, and no/never meant that the event has never been part of their life.

Stressful Life Events Variables:

Not being able to afford the things you need, *running out of money before the end of the month*, and *not having enough money to buy food* were each assessed individually as a dichotomous variable: ever vs. never. Those who experienced these difficulties at some point in their lives were put into the ever category, while those who never self-reported experiencing these events were included in the never category. There were not enough individuals with a previous diagnosis of diabetes to assess these questions using the four groups initially coded for: acute (only experienced the event in the last month),

chronic (experienced the event for several months or years), historical (only experienced the event in the past, but not now), and never. Other self-reported variables including *hearing gossip about someone you care about*, *hearing gossip about yourself*, *having a gambling problem*, or *having a problem with drugs* were coded in the same way because very few people fell into the acute and/or historical categories. Though there were enough individuals who reported *experiencing racism* in each of the chronic, historical, and never groups, participants who were in the chronic and historical groups were combined because their odds ratios were both significant and almost the same magnitude after adjusting for age and sex. Therefore suggesting that experiencing racism, no matter when, affected people's perceptions of control similarly. The only stressful life events variable that was coded differently was self-reported drinking problem. There were a substantial amount of individuals who had a previous drinking problem (i.e., historical problem), and very few that had an acute problem. Those with an acute problem (n = 10) were grouped with individuals who never had a drinking problem because when administering the questionnaire most of the people who reported an acute problem explained that they engaged in binge-drinking in the past month and at no other point in their lives. Having engaged in binge drinking once or twice in the past month likely was closer to never having a drinking problem, than having a chronic or historical drinking problem.

3.7 Analysis

Prior to analysis all data were assessed for data entry errors, a procedure known as "data cleaning". Specifically, the master excel file was imported in to SPSS and an approximate random sample of 10% of cases was generated. All cases randomly

identified were compared with original questionnaires to ensure the accuracy of the data, and if a data entry mistake was identified it was subsequently corrected. In addition, anthropometric data and family history data were compared with original questionnaires for each participant to ensure accuracy.

Data analyses were conducted using SPSS version 19.0. The demographic, health status, control and stress variables used in this analysis underwent univariate analyses to examine the distribution. For continuous variables (e.g., age, education level, etc.) mean, standard deviation, median with minimum, maximum values were generated. Some continuous variables were converted to categorical variables and were described in the Measures section (3.6) above. For categorical variables, frequencies were computed for each measure. For each variable the minimum and maximum values were also checked to ensure that no outliers were present.

Bivariate analyses were then completed using t-tests or Analysis of Variance (ANOVA) for continuous variables. Non-parametric tests, Mann-Whitney U, were used to perform bivariate analysis on continuous variables that were not normally distributed. Chi-square tests were performed to investigate associations between perceived control and sociodemographic variables, level of self-reported health, chronic disease status, self-reported stress, and burden of diabetes in the family. Chi-square tests were conducted on each control variable using the four category response and two-category response, and then results were compared to determine if there were differences in significant relationships when using the two response vs. four response control variables. Further analysis was conducted solely on the binary control variables because there were no major differences in relationships when comparing the two groupings of control

variables. In addition, interpretation of the findings is easier with two categories (low or high perceived control) versus a four point scale. The Bonferoni correction was applied to bivariable analysis to reduce the chance of committing Type 1 error.

A composite control measure combining the scores on the questions assessing control over health, emotions, and life was created by summing the response values together giving a minimum response value of 3 and a maximum value of 12. This was done because the study in which these questions were developed created a composite variable to assess global perceptions of control (121). However, after bivariate analysis it was determined that the composite measure did not fully describe participant's perceptions of control, because significant relationships between single control variables and other demographic, health, and stress markers at the bivariate and multivariate level (e.g., Mantel-Haenszel tests) were masked. No significant relationships between control over emotions and other variables were found, therefore no further analysis were conducted using control over emotions. An alpha level of $p = 0.05$ was used to determine statistical significance between relationships during bivariate analysis. Next, Mantel-Haenszel tests (2 x 2 x 2 tables) were performed to investigate any differences between sexes.

Multivariable logistic regression was used to identify predictors of perceived control over preventing diabetes and diabetes complications for those with a previous diagnosis of diabetes. Variables under consideration for inclusion in the models had to have a p-value alpha < 0.1, or were important variables to include in the model (e.g., diabetes status), underwent analysis controlling for age and sex. Backwards stepwise regression was performed for each outcome (perceived control over diabetic

complications and perceived control over diabetes prevention) separately for demographic/health status, chronic conditions, stress, and stressful life events. Analyses were done separately to ensure that there was enough power due to the small sample size of the outcome variable perceived control over diabetes complications (n = 99). Another reason the analysis was completed by these groupings is due to known relationships between some variables (e.g., chronic stress and negative impact of residential school). Residential school may be a major contributor to chronic stress in the community, but by itself it is also an important variable to explore. Spearman correlations between variables that remained significant were completed to help explain the results and identify any collinearity. Once multivariable logistic regression was completed for each category (demographic/health status, chronic conditions, stress, stressful life events, and diabetes in the family), a combined model was developed. Significant variables from each category were considered in the combined models. The combined models were also selected by backwards stepwise selection and based on community interests, relevance, and c-statistics.

Chapter 4

Results

4.1 Community Description – Demographic characteristics, health status, & stress markers

A total of 534 participants completed some portion of the study protocol. Seven participants were removed from final analysis because they had not completed the blood sample, one had yet to complete the stress and coping questionnaire in its entirety, five people were removed due to low comprehension of the stress and coping questions or only partial completion of questionnaire, and one was removed because it was determined that they were non-FN and thus did not meet criteria for inclusion in the study, leaving a final sample of 520 participants.

There were slightly more men (n = 274, 52.7%), than women (n = 246, 47.3%) who participated in the study. The sample was young with a median age of 34 years old for both sexes, a median of 36 years old for women (range: 18-73), and a median of 32 years old for men (range: 18-69). The majority of participants were unemployed, lived in Sandy Bay for the majority of their lives, and spoke an Aboriginal language (e.g., Saulteaux) fluently. For all demographic factors assessed, and shown in **table 4.1.1a**, there were no statistically significant differences between men and women at alpha < 0.05.

Table 4.1.1a Demographic characteristics of study population by sex

	Sex		
Characteristic	**Men** n (%)	**Women** n (%)	**Total** n (%)
Age*			
18-24	80 (29.2)	59 (24.0)	139 (26.7)
25-34	65 (23.7)	60 (24.4)	125 (24.0)
35-49	87 (31.8)	84 (34.1)	171 (32.9)
50 +	42 (15.3)	43 (17.5)	85 (16.3)
Mean (SD)	34.73 (13.044)	36.14 (12.624)	35.39 (12.854)
Marital status*			
Non-married	121 (44.2)	102 (41.5)	223 (42.9)
Married	140 (51.1)	138 (56.1)	278 (53.5)
Prefer not to answer	13 (4.7)	6 (2.4)	19 (3.7)
Level of education*			
≤ Grade 9	121 (44.2)	116 (47.2)	237 (45.6)
≥ Grade 10	148 (54.0)	125 (50.8)	273 (52.5)
Prefer not to answer	5 (1.8)	5 (2.0)	10 (1.9)
Employment status*			
Employed	53 (19.3)	48 (19.5)	101 (19.4)
Unemployed	221 (80.7)	198 (80.5)	419 (80.6)
Living in community*			
Whole life	176 (64.2)	150 (61.0)	326 (62.7)
≥½ and < whole life	69 (25.2)	58 (23.6)	127 (24.4)
Less than ½ of life	29 (10.6)	38 (15.4)	67 (12.9)
Aboriginal language*			
Fluent	176 (64.2)	152 (61.8)	328 (63.1)
Not fluent	98 (35.8)	94 (38.2)	192 (36.9)

*No statistically significant difference by sex

Among the selected demographic characteristics of the study population shown in **table 4.1.1b**, older participants were more likely to be fluent in an Aboriginal language and report that they were married.

Table 4.1.1b Select demographic characteristics of study population by age group

	Age			
Characteristic	**18 - 24**	**25 - 34**	**35 - 49**	**50 +**
Marital Status[a]				
Non-married	90 (68.2)	50 (42.0)	56 (33.7)	27 (32.1)
Married	42 (31.8)	69 (58.0)	110 (66.3)	57 (67.9)
Level of education				
≤ Grade 9	63 (46.0)	48 (39.7)	80 (47.6)	46 (54.8)
≥ Grade 10	74 (54.0)	73 (60.3)	88 (52.4)	38 (45.2)
Aboriginal language[a]				
Fluent	103 (74.1)	55 (44.0)	29 (17.0)	5 (5.9)
Not fluent	36 (25.9)	70 (56.0)	142 (83.0)	80 (94.1)

[a] statistically significant difference between age groups (P<0.001)

A high chronic disease prevalence was present in the study population (**table 4.2**): just below 70% of the sample had at least one chronic health condition that was self-reported or measured during study procedures. Just over 25% of the sample has diabetes, with another 6% (n = 32) having impaired fasting glucose which places them at increased risk for developing diabetes. The prevalence of hypertension was also very high, with 36% of the sample having previous or newly diagnosed high blood pressure. Risk factors for the development of chronic disease were also high. Women were statistically significantly more likely to be obese, including abdominal obesity, compared to men who participated in the study, prior to controlling for other variables. Women were also statistically significantly more likely than men to have dyslipidemia (19.3% vs. 30.2%). Despite the high prevalence of chronic conditions and risk factors for chronic disease, three quarters (76.5%) of participants rated their health as excellent/very good/good and one quarter rated their health as poor or fair.

Table 4.1.2a Health status of study population by sex (n = 520 unless otherwise stated)

	Sex		
Characteristic	**Men** n (%)	**Women** n (%)	**Total** n (%)
Ever smoked			
Yes	254 (92.7)	223 (90.7)	477 (91.7)
No	20 (7.3)	23 (9.3)	43 (8.3)
Current smoker			
Yes	229 (83.6)	197 (80.1)	424 (81.5)
No	45 (16.4)	49 (19.9)	96 (18.5)
Packyears[2] (n = 477)			
	7.2 (7.9)	7.2 (8.4)	7.2 years (8.1)
Diabetes			
Yes	67 (24.4)	65 (26.4)	132 (25.4)
No	207 (75.6)	181 (73.6)	388 (74.6)
Previous diagnosis[2] (n = 520)	52 (19.0)	48 (19.5)	100 (19.2)
New diagnosis (n = 420)	15 (6.8)	17 (8.6)	32 (7.6)
IFG (n = 420)	17 (7.7)	14 (4.7)	31 (7.4)
Hypertension (n = 517)			
Yes	106 (39.0)	79 (32.2)	185 (35.8)
No	166 (61.0)	166 (67.8)	332 (64.2)
Previous diagnosis[a] (n = 517)	49 (18.0)	59 (24.1)	108 (20.9)
New diagnosis[a] (n = 409)	56 (24.9)	19 (10.2)	75 (18.3)
Arthritis[1]			
Yes	21 (7.7)	31 (12.6)	52 (10.0)
No	253 (92.3)	215 (87.4)	468 (90.0)
Stroke[1]			
Yes	7 (2.6)	5 (2.0)	12 (2.3)
No	267 (97.4)	241 (98.0)	508 (97.7)
Heart Problems[1]			
Yes	22 (8.0)	12 (4.9)	34 (6.5)
No	252 (9.2)	234 (95.1)	486 (93.5)
Dyslipidemia [b] (n = 519)			
Yes	53 (19.3)	74 (30.2)	127 (24.5)
No	221 (80.7)	171 (69.8)	392 (75.5)
Abdominal Obesity [a] (n = 516)			
Yes	117 (43.2)	201 (82.0)	318 (61.6)
No	154 (56.8)	44 (18.0)	198 (38.4)
Obese [a] (n = 515)			
Yes	94 (34.7)	143 (58.6)	237 (46.0)
No	177 (65.3)	101 (41.4)	278 (54.0)
Vision Difficulties			
Yes	34 (12.4)	28 (11.4)	62 (11.9)
No	240 (87.6)	218 (88.6)	458 (88.1)
Mobility Difficulties[1,b]			
Yes	38 (13.9)	58 (23.6)	424 (81.5)
No	236 (86.1)	188 (76.4)	96 (18.5)
Limited due to health			

condition			
Yes	32 (11.7)	41 (16.7)	73 (14.0)
No	242 (88.3)	205 (83.3)	447 (86.0)
Number of Chronic Conditions (n = 513)			
None	100 (36.9)	62 (25.6)	162 (31.6)
1 condition	66 (24.3)	68 (28.1)	134 (26.1)
2 conditions	59 (21.8)	48 (19.8)	107 (20.8)
3 conditions	32 (11.8)	35 (14.5)	67 (13.1)
4 or 5 conditions	14 (5.2)	29 (12.0)	43 (8.4)
Self-Rated Health			
Poor or Fair	59 (21.5)	63 (25.6)	122 (23.5)
Good, VG, or Excellent	215 (78.5)	183 (74.4)	398 (76.5)

[1] Self reported
[2] Mean (SD)
[a] statistically significant difference between men and women (P<0.001)
[b] statistically significant difference between men and women (P<0.01)

There were statistically significant differences between the selected health status characteristics of the population. Older participants were more likely to have diabetes, hypertension, dyslipidemia and abdominal obesity compared to younger participants.

Table 4.1.2b Select health status characteristics of study population by age group (n = 520 unless otherwise stated)

	Age			
Characteristic	**18 - 24**	**25 - 34**	**35 - 49**	**50 +**
Diabetes[a]				
Yes	6 (4.3)	16 (12.8)	55 (32.2)	55 (64.7)
No	133 (95.7)	109 (87.2)	116 (67.8)	30 (35.3)
HTN[a]				
Yes	22 (15.9)	33 (26.4)	69 (40.8)	61 (71.8)
No	116 (84.1)	92 (73.6)	100 (59.2)	24 (28.2)
Dyslipidemia[a]				
Yes	16 (11.5)	35 (28.0)	45 (26.3)	31 (36.9)
No	123 (88.5)	90 (72.0)	126 (73.7)	53 (63.1)
Abdominal obesity[a]				
Yes	67 (48.6)	81 (64.8)	108 (64.3)	62 (72.9)
No	71 (51.4)	44 (35.2)	60 (35.7)	23 (27.1)

[a] statistically significant difference between age groups (P≤0.001)

Women were more likely than men to report higher levels of perceived stress over their entire life and higher levels of acute stress compared to men (59.4% vs. 48.5%, and 65.3% vs. 49.5% respectively). However no statistically significant difference between men and women were found for individuals' perceptions of their stress experienced over their entire life compared to other people their age, and perceived negative impact of residential school. Even though the sample is relatively young, 34.2% of participants (n = 178) indicated that their life had been negatively affected (quite a bit or a lot) by residential school.

Table 4.1.3 Self-reported stress markers (n = 520 unless otherwise stated)

	Sex		
Characteristic	**Men** n (%)	**Women** n (%)	**Total** n (%)
Stress over entire life			
None / A Little Bit	141 (51.5)	100 (40.6)	241 (46.3)
Quite a Bit / A Lot	133 (48.5)	146 (59.4)	279 (53.7)
Stress over entire life compared to others the same age			
None / A Little Bit	149 (54.4)	125 (50.8)	274 (52.7)
Quite a Bit / A Lot	125 (45.6)	121 (49.2)	246 (47.3)
Negative impact of residential school			
None / A Little Bit	184 (67.2)	158 (64.2)	342 (65.8)
Quite a Bit / A Lot	90 (32.8)	88 (35.8)	178 (34.2)
Acute stress (stress over the past month)			
Less Stress	138 (50.5)	85 (34.7)	223 (43.1)
More Stress	135 (49.5)	160 (65.3)	295 (56.9)

Select self-reported stressful life events are reported below in **table 4.1.4**. Over 20% of participants reported not having enough money to buy food at some point in their life, and 59% of participants chronically run out of money prior to the end of the month. Many participants did not believe that community resources were equally distributed, and only about a third of participants said that they did not have to wait a long time to get help from community services. Of note is that more than half of the participants (59.3%)

thought that they could do something to make Sandy Bay a better place to live at some point in their lives.

4.1.4 Selected Self-Reported Stressful Life Events

Event	Exposure to Event n (%)			
	Acute (past month)	Chronic (past year and longer)	Historical (in the past but not the past year)	No/Never
Unable to afford things you need	23 (4.4)	245 (47.1)	62 (11.9)	190 (36.5)
Run out of money before the end of the month	38 (7.3)	307 (59.0)	17 (3.3)	158 (30.4)
Not enough money to buy food	7 (1.3)	97 (18.7)	36 (6.9)	380 (73.1)
Felt lonely	28 (5.4)	327 (62.9)	42 (8.1)	123 (23.7)
Someone close died	23 (4.4)	295 (56.7)	147 (28.3)	55 (10.6)
Friend or family member seriously ill	16 (3.1)	224 (43.1)	96 (18.5)	184 (35.4)
Own health poor	16 (3.1)	126 (24.2)	34 (6.5)	344 (66.2)
Drinking problem	10 (1.9)	106 (20.4)	104 (20.0)	300 (57.7)
Grambling problem	8 (1.5)	78 (15.0)	29 (5.6)	405 (77.9)
Drug problem	6 (1.2)	86 (16.5)	60 (11.5)	268 (70.8)
Experienced Racism	3 (0.6)	142 (27.3)	106 (20.4)	269 (51.7)
Transportation problems	31 (6.0)	209 (40.2)	44 (8.5)	236 (45.4)
Long wait for help from community services	20 (3.8)	284 (54.6)	35 (6.7)	181 (34.8)
Overcrowding	25 (4.8)	224 (43.1)	75 (14.4)	196 (37.7)
Felt bored	21 (4.0)	297 (57.1)	17 (3.3)	185 (35.6)
Housing is equal	4 (0.8)	56 (10.8)	8 (1.5)	452 (86.9)
Equal job opportunities	5 (1.0)	73 (14.0)	8 (1.5)	434 (83.4)
Recreation & sports are equal	13 (2.5)	180 (34.6)	18 (3.5)	209 (59.4)
Believe they can make Sandy Bay a better place to live	21 (4.0)	272 (52.3)	15 (2.9)	212 (40.7)
Gossip is a problem	10 (1.9)	422 (81.2)	7 (1.3)	81(15.6)
Missed out on a job b/c not related	19 (3.7)	203 (39.0)	49 (9.4)	249 (47.9)

The burden of diabetes among families of individuals who participated in the study was great, with 80.4% of the participants reporting that at least one relative (primary or secondary) had diabetes. Of those who reported having a positive family history of diabetes, 82.5% (345) had at least one primary relative with diabetes, of which 16% had five or more primary relatives with diabetes. Individuals with a family member

diagnosed with diabetes had between 1 and 13 primary family members with diabetes, and up to 18 family members with diabetes once secondary relatives were included.

4.1.5 Burden of Diabetes in the Family

	Sex		
Characteristic	**Men** n (%)	**Women** n (%)	**Total** n (%)
Family member with diabetes[1] (n = 520)			
No / Unsure	66 (24.1)	36 (14.6)	102 (19.6)
Yes	208 (75.9)	210 (85.4)	418 (80.4)
Primary relative with diabetes[2] (n = 418)			
No	36 (17.3)	37 (17.6)	73 (17.5)
Yes	172 (82.7)	173 (82.4)	345 (82.5)
Number of primary relatives with diabetes (n = 345)			
1	70 (40.7)	63 (36.4)	133 (38.6)
2 – 4	76 (44.2)	82 (47.4)	158 (45.8)
5 +	26 (15.1)	28 (16.2)	54 (15.7)
Number of primary and secondary relatives with diabetes[3] (n = 418)			
1	62 (29.8)	47 (22.4)	109 (26.1)
2 – 4	96 (46.2)	109 (51.9)	205 (49.0)
5 +	50 (24.0)	54 (25.7)	104 (24.9)
Proportion of family with diabetes excluding children[4] (n = 520)			
None	68 (24.8)	40 (16.3)	108 (20.8)*
1 – 25%	124 (45.3)	116 (47.2)	240 (46.2)
26 – 50%	59 (21.5)	62 (25.2)	121 (23.2)
> 50%	23 (8.4)	28 (11.4)	51 (9.8)

[1]family member with diabetes: participant said that at least a mother, father, sister, brother, child, or grandparent was diagnosed with Type 2 diabetes
[2]primary relative: mother, father, sister(s), and/or brother(s)
[3]secondary relative: maternal grandmother, maternal grandfather, paternal grandmother, paternal grandfather, daughter(s), and/or son(s)
[4](# of grandparents with diabetes + # of parents with diabetes + # siblings with diabetes) / (total # of grandparents + parents + siblings)
*108 includes the 102 participants that did not have a family member with diabetes and 6 participants whose only family members with diabetes were their children.

4.2 Research Objective 1: To determine the distribution of perceived levels of control over life and general health

A substantial number of individuals (47.7%) reported that they had little or no control over their life, and slightly fewer individuals indicated that they had little or no control over their physical health (41.7%).

Table 4.2.1 Perceived Control Over Health and Life

Variable	**Level of self-reported perceived control** n (%)			
	None	**A Little Bit**	**Quite a Bit**	**A Lot**
Personal influence over Life in General	71 (13.7)	177 (34.0)	135 (26.0)	137 (26.3)
Personal influence over Physical Health	77 (14.8)	140 (26.9)	137 (26.3)	166 (31.9)

As seen in **table 4.2.2**, those with a higher level of education were significantly more likely to report higher perceptions of control over life compared to those with a lower education, which held true even after controlling for sex. Being employed was positively associated with a higher perceived control over life when the entire sample was assessed ($p = 0.005$) and when only men were included ($p = 0.007$), but not when women were assessed separately ($p = 0.123$). Being married was significantly associated with having a high level of perceived control over health for women only. Men and women who reported high levels of chronic lifetime stress were most likely to report that they had quite a bit or a lot of control over their lives. Conversely, the relationship between level of acute stress and control over life only tended toward significance for women, where women with low levels of acute stress reported higher perceived control over life. A significant positive relationship between obesity and control over life was found for men, and tended towards significance for the entire sample, but remained non-significant for women. No other variables assessed and shown in **table 4.2.2** were found to be

significantly related to perceptions of control over life. A1c level was not found to be associated with perceived control over life in general ($p = 0.920$).

Having a higher level of education was positively related to high perceived control over physical health for both men and women. Being employed was associated with a higher perception of control over health for men ($p = 0.053$) and the whole sample ($p = 0.015$), but not women when assessed alone ($p = 0.115$). When all participants were included in the analysis, high levels of chronic lifetime stress were associated with high levels of perceived control over physical health; however, when assessed separately no relationship was found for women. Men and women who reported low levels of acute stress were more likely to say that they had high levels of perceived control over their health. No other chronic disease status or health indicators were significantly related to perceived control over health. A1c level was not related to perceived level of control over health ($p = 0.760$).

Table 4.2.2 Bivariate Analysis of Perceived Control over Life and Physical Health[1]

Variable	Personal influence over Life in General			Personal influence over Physical Health		
	None or A Little Bit	Quite a Bit or A Lot	p value	None or A Little Bit	Quite a Bit or A Lot	p value
Socio-demographic variables						
Sex						
Male	131 (47.8)	143 (52.2)	0.958	110 (40.1)	164 (59.9)	0.442
Female	117 (47.6)	129 (52.4)		107 (43.5)	139 (56.5)	
Employment Status						
No	214 (51.1)	205 (48.9)	0.005	186 (44.4)	233 (55.6)	0.015
Yes	34 (33.7)	67 (66.3)		31 (30.7)	70 (69.3)	
Age Group Quartile						
18-24	59 (42.4)	80 (57.6)	0.827	58 (41.7)	81 (58.3)	0.955
25-34	67 (53.6)	58 (46.4)		53 (42.4)	72 (57.6)	
35-49	86 (50.3)	85 (49.7)		69 (40.4)	102 (59.6)	
50 +	36 (42.4)	49 (57.6)		37 (43.5)	48 (56.5)	
Level of Education						
≤ Grade 9	139 (58.6)	98 (41.4)	0.003	117 (49.4)	120 (50.6)	0.004
≥ Grade 10	110 (40.3)	163 (59.7)		95 (34.8)	178 (65.2)	
Marital Status (n = 501)						
Not-married	103 (46.2)	120 (53.8)	0.600	83 (37.2)	140 (62.8)	0.098
Married	135 (48.6)	143 (51.4)		124 (44.6)	154 (55.4)	
Self reported stress						
Chronic Stress						
None / A Little Bit	133 (55.2)	108 (44.8)	0.004	113 (46.9)	128 (53.1)	0.030
Quite a Bit / A Lot	115 (41.2)	164 (58.8)		104 (37.3)	175 (62.7)	
Acute Stress						
Less Stress	120 (44.8)	148 (55.2)	0.147	93 (34.7)	175 (65.3)	0.004
More Stress	128 (51.2)	270 (48.8)		124 (49.6)	126 (50.4)	
Negative impact of residential school						
None / A Little Bit	168 (49.1)	174 (50.9)	0.368	145 (42.4)	197 (57.6)	0.672
Quite a Bit / A Lot	80 (44.9)	98 (55.1)		72 (40.4)	106 (59.6)	
Chronic Disease Status						
Previous Diabetes Status						
No	197 (46.9)	223 (53.1)	0.464	175 (41.7)	345 (58.3)	0.955
Yes	51 (51.0)	49 (49.0)		42 (42.0)	58 (58.0)	
New Diabetes Status (n = 420)						
No	169 (47.3)	188 (52.7)	0.546	152 (42.6)	205 (57.4)	0.431
IFG	15 (48.4)	16 (51.6)		11 (35.5)	20 (64.5)	
Yes	13 (40.6)	19 (59.4)		12 (37.5)	20 (62.5)	
Dyslipidemia						
No	195 (49.7)	197 (50.3)	0.087	166 (42.3)	226 (57.7)	0.557
Yes	52 (40.9)	75 (59.1)		50 (39.4)	77 (60.6)	
Abdominal Obesity						
No	99 (50.0	99 (50.0)	0.339	89 (44.9)	109 (55.1)	0.186
Yes	146 (45.9)	172 (54.1)		125 (39.3)	193 (60.7)	
Obese						
No	142 (51.1)	136 (48.9)	0.087	125 (45.0)	153 (55.0)	0.102
Yes	103 (43.5)	134 (56.5)		89 (37.6)	148 (62.4)	

Variable	Personal influence over Life in General			Personal influence over Physical Health		
	None or A Little Bit	Quite a Bit or A Lot	p value	None or A Little Bit	Quite a Bit or A Lot	p value
# of Chronic Conditions						
0	85 (52.5)	77 (47.5)		69 (42.6)	93 (57.4)	
1	60 (44.8)	74 (55.2)		58 (43.3)	76 (56.7)	
2	52 (48.6)	55 (51.4)	0.151	42 (39.3)	65 (60.7)	0.609
3	30 (44.8)	37 (55.2)		26 (38.8)	41 (61.2)	
4 - 5	17 (39.5)	26 (60.5)		18 (41.9)	25 (58.1)	
Hypertension						
No	165 (49.7)	167 (50.3)	0.200	139 (41.9)	193 (58.1)	0.865
Yes	81 (43.8)	104 (56.2)		76 (41.1)	109 (58.9)	
SRH						
Poor / Fair	61 (50.0)	61 (50.0)	0.563	55 (45.1)	67 (54.9)	0.394
G, VG, Excellent	187 (47.9)	211 (53.0)		162 (40.7)	236 (59.3)	

[1]n = 520 unless otherwise specified

Bonferoni correction 0.003.

# of chronic conditions and age quartile groups: χ^2 for linear association

4.3 Research Objective 2: To determine the proportion of individuals who believe they can 'control'/prevent diabetes or diabetes complications

A substantial number of individuals who had not been previously diagnosed with diabetes (47.8%) reported that they had little or no control over diabetes prevention, and 42% of individuals with a previous diagnosis of diabetes at the time they completed the study thought they had little or no control over preventing diabetic complications.

Table 4.3.1 Perceived Control over Diabetes Prevention, and Perceived Control over Diabetic Complications

Variable	Level of self-reported perceived control n (%)			
	None	A Little Bit	Quite a Bit	A Lot
Personal influence over Diabetes Prevention	103 (24.5)	98 (23.3)	83 (19.8)	136 (32.4)
Personal influence over Diabetic Complications	20 (20.0)	22 (22.0)	18 (18.0)	39 (39.0)

Participants' perceptions of prevention of diabetes were associated with level of education for the entire sample ($p = 0.042$), and when men were assessed alone ($p = 0.079$). Those with a higher level of education were more likely to have higher perceived control. Being employed was positively associated with high perceptions of control, but not when men ($p = 0.200$) and women ($p = 0.064$) were assessed separately. Experiencing quite a bit or a lot of negative effects from residential school was positively associated with having high levels of control. Self-rated health was positively associated with perceived control over diabetes prevention for men only, with those with better self-rated health having more perceived control ($p = 0.019$). Dyslipidemia was positively associated with high levels of perceived control ($p = 0.008$), though when the sexes were assessed separately they relationship was weaker (men: $p = 0.078$, women $p = 0.056$). Being clinically obese was negatively associated with perceived control over diabetes

prevention for women only (p = 0.051). For men, as the number of chronic conditions increased, perceptions of control over diabetes prevention also increased (p = 0.019). For those without a previous diagnosis of diabetes, A1c level was not related to level of perceived control over preventing diabetes (p = 0.768).

Burden of diabetes in the family was not associated with level of perceived control over diabetes prevention when measured as: the proportion of primary relatives with diabetes (p = 0.731), the proportion of relatives (excluding children) with diabetes (p = 0.794), the number of primary relatives with diabetes (p = 0.984), and the total number of family members (excluding children) with diabetes (p = 0.831). Being the caretaker of a family member with diabetes was significantly associated with higher levels of perceived control for the group as a whole (p = 0.037), and men alone (p = 0.042).

For participants who self-reported a diagnosis of diabetes there were also significant bivariate relationships. A high level of education was associated with high levels of perceived control. Having high levels of acute stress was associated with low perceived levels of control for men, and chronic stress was associated with high levels of perceived control for the sample as a whole (p = 0.008), and women only (p = 0.002). Having dyslipidemia was also related to having higher levels of perceived control over diabetic complications. A1c level was not related to level of perceived control over prevention of diabetic complications (p = 0.481) for those who had a previous diagnosis of diabetes at the time they participated in the research study.

The burden of diabetes in the family is not associated with perceived control over preventing diabetic complications when measured as: the total number of primary relatives with diabetes (p = 0.164), total number of relatives with diabetes (excluding

children) with diabetes ($p = 0.251$), or the proportion of primary relatives with diabetes ($p = 0.229$). However, women who never had to be the primary caretaker of a relative with diabetes were significantly more likely to believe that they had higher control over preventing diabetes complications.

Table 4.3.2 Bivariate Analysis of Perceived Control over Diabetes Prevention, and Perceived Control over Diabetic Complications

	Control Prevention – No Previous Diabetes[1]			Control Prevention – Previous Diabetes[2]		
Variable	**None or A Little Bit**	**Quite a Bit or A Lot**	**p-value**	**None or A Little Bit**	**Quite a Bit or A Lot**	**p-value**
Socio-demographic variables						
Sex						
Male	110 (54.7)	112 (50.5)	0.465	23 (45.1)	28 (54.9)	0.582
Female	91 (45.3)	107 (48.9)		19 (39.6)	29 (60.4)	
Aboriginal Language						
Not fluent	82 (46.3)	95 (53.7)	0.592	6 (40.0)	9 (60.0)	0.837
Fluent	119 (49.0)	124 (51.0)		36 (42.4)	48 (57.6)	
Employment Status						
No	169 (50.6)	165 (49.4)	0.033	36 (42.9)	48 (57.1)	0.843
Yes	32 (37.2)	54 (62.8)		6 (40.0)	9 (60.0)	
Marital Status (n = 403, n = 97)						
Not married	80 (44.2)	101 (55.8)	0.287	17 (41.5)	24 (58.5)	0.894
Married	110 (49.5)	112 (50.5)		24 (42.9)	32 (57.1)	
Level of Education						
≤ Grade 9	96 (53.6)	83 (46.4)	0.045	33 (57.9)	24 (42.1)	0.003
≥ Grade 10	101 (43.5)	131 (56.5)		8 (19.5)	33 (80.5)	
Self reported stress						
Residential School						
None/ A Little Bit	155 (51.2)	148 (48.8)	0.032	20 (52.6)	18 (47.4)	0.108
Quite a Bit/ A Lot	46 (39.3)	71 (60.7)		22 (36.1)	39 (63.9)	
Acute Stress (n = 418)						
Less Stress	98 (45.6)	117 (54.4)	0.295	19 (36.5)	33 (63.5)	0.216
More Stress	103 (50.7)	100 (49.3)		23 (48.9)	57 (57.6)	
Chronic Stress						
None/ A Little Bit	98 (50.5)	96 (49.5)	0.315	26 (56.6)	20 (43.5)	0.011
Quite a Bit/ A Lot	103 (45.6)	123 (54.4)		16 (30.2)	37 (69.8)	
Chronic Disease Status						
Diabetes / Diabetes Complications (no/yes)						
No	171 (47.9)	186 (52.1)	0.995	23 (36.5)	40 (63.5)	0.118
IFG (yes)	15 (48.4)	16 (51.6)		19 (52.8)	17 (47.2)	
New	15 (46.9)	17 (53.1)				
SRH						
Poor or Fair	39 (51.3)	37 (48.7)	0.508	22 (48.9)	23 (51.1)	0.238
G, VG, or Excellent	162 (47.1)	182 (52.9)		20 (37.0)	34 (63.0)	
Dyslipidemia						
No	172 (51.2)	164 (48.8)	0.011	32 (58.2)	23 (41.8)	0.003
Yes	29 (34.9)	54 (65.1)		10 (22.7)	34 (77.3)	
Obese						
No	108 (46.0)	127 (54.0)	0.449	18 (42.9)	24 (57.1)	0.862
Yes	90 (49.7)	91 (52.4)		23 (41.1)	33 (58.9)	
Abdominal Obesity						
No	86 (49.7)	87 (50.3)	0.446	10 (41.7)	14 (58.3)	0.987
Yes	112 (45.9)	132 (54.1)		31 (41.9)	57 (58.1)	

Variable	Control Prevention – No Previous Diabetes[1] None or A Little Bit	Quite a Bit or A Lot	p-value	Control Prevention – Previous Diabetes[2] None or A Little Bit	Quite a Bit or A Lot	p-value
# of Chronic Conditions / Co-morbidities (no/yes)						
0 (no)	81 (50.0)	81 (50.0)		3 (37.5)	5(62.5)	N/A
1 (yes)	66 (51.2)	63 (48.8)	0.334	38 (42.2)	52 (27.8)	
2	31 (40.3)	46 (59.7)				
3, 4 or 5	19 (41.3)	27 (58.7)				
HTN						
No	152 (49.4)	156 (50.6)	0.202	22 (42.3)	30 (57.7)	0.983
Yes	46 (42.2)	63 (57.8)		20 (42.6)	27 (57.4)	
Family Burden of Diabetes						
Caretaker of family member with diabetes						
No	184 (49.7)	186 (50.3)	0.040	36 (46.2)	42 (53.8)	0.151
Yes	17 (34.0)	33 (66.0)		6 (28.6)	15 (71.4)	
Diabetes - Family						
No	51 (51.0)	49 (49.0)	0.474	1 (50.0)	1 (50.0)	0.830
Yes	150 (46.9)	170 (53.1)		41 (42.3)	56 (57.7)	

[1]n = 420 unless otherwise specified

[2]n = 99 unless otherwise specified

Bonferoni correction 0.003.

# of chronic conditions and age quartile groups: χ^2 for linear association

4.4 Research Question 3: To determine what factors are related to perceived control over diabetes prevention

Several demographic factors were found to influence the odds of participants having a higher perception of their own ability to prevent diabetes. The odds of having higher perceptions of control over prevention diabetes are greater for participants who have completed at least grade 10 (OR 1.531), are currently employed (OR 1.461), and are currently or have been a caregiver for a family member with diabetes at some point in their life (OR 1.905) after controlling for age and sex. Those who are married have reduced odds of believing that they have high control over preventing diabetes compared to those who are married, controlling for age and sex. Those are fluent in an Aboriginal language have reduced odds of believing they have high control over preventing diabetes compared to those who are not fluent after controlling for age and sex. Though not statistically significant ($p = 0.072$), those who had a greater proportion of primary relatives with diabetes had lower odds (OR 0.374) of having a high belief in their ability to prevent diabetes after controlling for age and sex.

Several stressful life events also influenced participants' perceptions about diabetes prevention after controlling for age and sex. Participants had greater odds of having a high belief in the controllability of diabetes prevention if they reported hearing gossip about themselves (OR 1.902) or someone they cared about (OR 1.781) at some point in their lives. Participants who had a historical drinking problem (i.e., had a drinking problem in the past but not currently) had greater odds of believing that they could do quite a bit or a lot to prevent the onset of diabetes compared to those who never had a drinking problem and those who had an ongoing chronic drinking problem. Participants who reported experiencing racism at some point in their lives were also more

likely to report higher perceptions of perceived control (OR 2.003). Of note is that not having enough money to buy food, running out of money before the end of the month, and not being able to afford the things you need did not affect individuals' perceptions of their own ability to prevent diabetes in a statistically significant way. The only chronic condition that affected the odds of reporting high perceptions of control after controlling for age and sex was having dyslipidemia (OR 1.810).

Table 4.4.1 Logistic regression results of perceived control over diabetes prevention adjusting for age and sex

Predictor	Odds Ratio	95% CI	P- value
Demographic & Health Status			
≥ Grade 10	1.531	1.030, 3.376	0.035
Married	0.649	0.425, 0.991	0.045
Employed	1.461	0.878, 2.431	0.145
Fluent in an Aboriginal language	0.568	0.355, 0.908	0.018
Caregiver of someone with diabetes	1.905	1.018, 3.562	0.044
Good, Very Good, and Excellent SRH	1.175	0.710, 1.947	0.530
Number of primary relatives with diabetes	0.939	0.838, 1.052	0.279
Number of primary and secondary relatives with diabetes	0.968	0.889, 1.054	0.460
Proportion of primary relatives with diabetes	0.374	0.128, 1.094	0.072
Proportion of primary and secondary relatives with diabetes	0.459	0.131, 1.605	0.223
Stress			
Quite a bit or a lot of perceived negative impact from residential school	1.404	0.895, 2.202	0.140
Quite a bit or a lot of chronic stress	1.235	0.835, 1.826	0.290
High level of acute stress	0.803	0.540, 1.193	0.273
Stressful Life Events			
Not able to afford things you need	1.201	0.802, 1.796	0.374
Running out of money before the end of the month at some point in their life	1.065	0.695, 1.632	0.771
Not enough money to buy food at some point in their life	0.940	0.604, 1.461	0.783
Hearing gossip about someone you care about at some point in their life	1.781	1.150, 2.760	0.010
Hearing gossip about yourself at some point in their life	1.902	1.263, 2.865	0.002
Experiencing racism at some point in life	2.003	1.350, 2.972	0.001
Gambling problem at some point in their life	0.994	0.621, 1.590	0.979
Drinking problem			
Chronic	0.860	0.525, 1.409	0.550
Historical	1.764	1.017, 3.061	0.043
Problem with drugs at some point in their life	0.938	0.609, 1.444	0.772
Chronic Conditions			
IFG	0.873	0.414, 1.842	0.722
Newly diagnosed diabetes	0.818	0.386, 1.732	0.600
HbA1c	0.920	0.754, 1.122	0.409
Fasting glucose	0.946	0.841, 1.063	0.348
HTN	1.102	0.687, 1.766	0.687

Predictor	Odds Ratio	95% CI	P- value
Obese	0.817	0.587, 1.220	0.323
Abdominal obesity	1.027	0.667, 1.581	0.904
Dyslipidemia	1.810	1.090, 3.004	0.022
Presence of a chronic condition	1.002	0.662, 1.517	0.993
Self-reported mobility difficulties	0.800	0.459, 1.394	0.431
Self-reported vision difficulties	0.713	0.371, 1.370	0.310
Limited in some kind of activity	1.354	0.706, 2.599	0.362
Arthritis	0.513	0.503, 2.405	0.812

All variables are adjusted for age and sex.

After combining variables that statistically influenced the odds of having a higher belief in the controllability of preventing diabetes in to models several remained significant. Being the caregiver of a family member with diabetes increased the odds of having higher control beliefs by approximately two times after controlling for sex, and age and language, both of which remained significant in the model. Experiencing racism increased the odds of having higher perceptions of control by just over 1.5 times compared to those who did not report experiencing racism after controlling for hearing gossip about yourself, age, and sex.

Table 4.4.2 Logistic regression models of perceived control over diabetes prevention for demographic, stressful life events, and chronic disease status

Predictor	Odds Ratio	95% CI	P- value
Demographic Model[1]			
Age	1.039	1.018, 1.061	0.000
Sex	0.958	0.645, 1.422	0.830
Caretaker of family member with diabetes	1.962	1.043, 3.691	0.037
Fluent in an Aboriginal language	0.556	0.347, 0.893	0.015
Stressful Life Events Model[2]			
Age	1.029	1.011, 1.048	0.001
Sex	0.989	0.659, 1.483	0.956
Hearing gossip about yourself at some point in their life	1.669	1.095, 2.545	0.017
Experiencing racism at some point in their life	1.803	1.203, 2.703	0.004
Chronic Conditions Model[3]			
Age	1.023	1.005, 1.041	0.012
Sex	0.957	0.646, 1.418	0.826
Dyslipidemia	1.810	1.090, 3.004	0.022

No stress model was created because there were no variables significant at ≤0.1.

[1]Order of variables removed during backward multivariable logistic regression: employment status, marital status, proportion of primary relatives with diabetes, level of education.

[2]Order of variables removed during backward multivariable logistic regression: Hearing gossip about someone you care about, drinking problem.

[3]HbA1c, fasting glucose, and current diabetes status were forced into the model to ensure that they did not become significant when assessed with other variables. HbAlc, fasting glucose and current diabetes status remained not-significant and thus were not included in the model.

The model shown in table 4.4.4 includes variables that remained significant in table 4.4.2 in to an overall model. This model incorporates variables that remained significant after backwards stepwise logistic regression and had the highest c-statistic (0.656). The model below indicates that after controlling for age, sex, hearing gossip

about someone you care about and dyslipidemia, experiencing racism increases the odds of having higher beliefs of the controllability of diabetes prevention by 1.8 times.

Table 4.4.3 Logistic regression model of perceived control over diabetes prevention (n = 419)

Predictor	Odds Ratio	95% CI	P- value
Model A[1]			
Age	1.027	1.008, 1.045	0.004
Sex	1.041	0.691, 1.569	0.847
Dyslipidemia	1.810	1.078, 3.039	0.025
Hearing gossip about yourself at some point in their life	1.709	1.116, 2.615	0.014
Experiencing racism at some point in their life	1.795	1.194, 2.698	0.005

[1]Order of variables removed during backward multivariable logistic regression: Caretaker of family member with diabetes, language.

4.5 Research Objective 4: To determine what factors are related to perceived control over the prevention of diabetic complications

Having a higher level of education (grade 10 or more) increased the odds of having a higher perception of control over diabetes prevention 6 times compared to those with a lower level of education after controlling for age and sex. No other demographic variables were remained significant after controlling for age and sex. Both reporting experiencing significant negative effects from residential school and high chronic stress increased the odds by just under 3 times of reporting a belief that they could do quite a bit or a lot to prevent themselves from getting diabetic complications, after controlling for age and sex. Having dyslipidemia increases the odds over 4.5 times of reporting higher beliefs in control over diabetes prevention compared to those who have normal triglyceride and HDL-cholesterol levels. Though not statistically significant at alpha of <0.05, but at alpha of 0.1, participants who had controlled diabetes (defined as HbA1c under 9) were less likely to believe that they had greater control over the prevention of diabetes complications.

Table 4.5.1 Logistic regression results of perceived control over the prevention of diabetic complications adjusting for age and sex

Predictor	Odds Ratio	95% CI	P- value
Demographic & Health Status			
≥ Grade 10	6.074	2.279, 16.190	0.000
Married	0.996	0.434, 2.282	0.992
Employed	1.123	0.364, 3.468	0.840
Fluent in an Aboriginal language	1.107	0.332, 3.690	0.868
Caregiver of someone with diabetes	2.346	0.798, 6.895	0.121
Good, Very good or excellent SRH	1.598	0.709, 3.604	0.259
Number of primary relatives with diabetes	0.896	0.771, 1.041	0.152
Number of primary and secondary relatives with diabetes	0.993	0.824, 1.056	0.275
Proportion of primary relatives with diabetes	0.485	0.115, 2.052	0.325
Proportion of primary and secondary relatives with diabetes	0.576	0.103, 3.214	0.529
Stress			
Quite a bit or a lot of perceived negative impact from residential school	2.988	1.142, 7.820	0.026
Quite a bit or a lot of chronic stress	2.979	1.293, 6.861	0.010
High level of acute stress	0.586	0.260, 1.322	0.198
Stressful Life Events			
Not able to afford things you need at some point in their life	0.621	0.261, 1.474	0.280
Run out of money before the end of the month at some point in their life	0.802	0.338, 1.902	0.616
Not enough money to buy food at some point in their life	0.687	0.283, 1.666	0.406
Hearing gossip about someone you care about at some point in their life	3.704	1.489, 9.214	0.005
Hearing gossip about yourself at some point in their life	2.090	0.923, 4.736	0.077
Experiencing racism at some point in their life	2.985	1.608, 9.877	0.003
Gambling problem at some point in their life	1.391	0.531, 3.647	0.502
Drinking problem			
Chronic	0.402	0.125, 1.295	0.127
Historical	1.746	0.663, 4.598	0.259
Problem with drugs	2.629	0.755, 9.153	0.129
Chronic Conditions			
HbA1c	1.080	.899, 1.296	0.411

Predictor	Odds Ratio	95% CI	P- value
Fasting glucose	1.030	0.932, 1.137	0.563
Length of time with diabetes	0.992	0.943, 1.044	0.761
HbA1c controlled	0.492	0.215, 1.124	0.092
HTN	0.789	0.308, 2.067	0.642
Obese	0.918	0.368, 2.292	0.885
Abdominal obesity	0.773	0.263, 2.278	0.641
Dyslipidemia	4.762	1.881, 12.057	0.001
Presence of diabetic complication(s)	0.537	0.230, 1.258	0.153
Self-reported mobility difficulties	0.534	0.225, 1.268	0.155
Self-reported vision difficulties	0.494	0.176, 1.384	0.180
Limited in some kind of activity	0.666	0.274, 1.615	0.368
Arthritis	0.656	0.248, 1.737	0.396

All variables are adjusted for age and sex.

Experiencing racism remained significantly associated with high perceptions of control over the prevention of diabetes when controlling for hearing gossip about someone you care about, age and sex. All other models shown in table 4.5.2 are the same as shown in table 4.5.1 because there was only one variable that remained significant when in the model with age and sex.

Table 4.5.2 Logistic regression models of perceived control over prevention of diabetic complications for demographic, stress, stressful life events, and chronic disease status

Predictor	Odds Ratio	95% CI	P- value
Demographic Model			
Age	0.998	0.958, 1.040	0.921
Sex	0.637	0.257, 1.578	0.330
≥ Grade 10	6.074	2.279, 16.190	0.000
Stress Model 1			
Age	0.961	0.921, 1.004	0.076
Sex	0.782	0.339, 1.799	0.562
Quite a bit or a lot of perceived negative impact from residential school*	2.988	1.142, 7.820	0.026
Stress Model 2			
Age	0.981	0.945, 1.020	0.338
Sex	0.921	0.397, 2.136	0.848
Quite a bit or a lot of chronic stress*	2.979	1.293, 6.861	0.010
Stressful Life Events Model[1]			
Age	0.997	0.957, 1.039	0.890
Sex	0.482	0.187, 1.241	0.130
Hearing gossip about someone you care about at some point in their life	2.899	1.115, 7.541	0.029
Experiencing racism at some point in their life	3.202	1.252, 8.187	0.015
Chronic Conditions Model[2]			
Age	0.994	0.995, 1.035	0.779
Sex	1.154	0.475, 2.803	0.752
Dyslipidemia	4.762	1.881, 12.057	0.001

[1]Order of variables removed during backward multivariable logistic regression: Hearing gossip about yourself**.**

[2]Order of variables removed during backward multivariable logistic regression: HbA1c controlled (yes/no). HbA1c, fasting glucose, and current diabetes status were forced into the model separately to ensure that they did not become significant when assessed with other variables. HbAlc, fasting glucose and current diabetes status remained not-significant and thus were not included in the model.

*Residential school and level of perceived chronic stress were not included in the same model because in theory the negative effects of residential school are known to be a substantial source of chronic stress for many individuals in the community. One was not picked over the other because they were both separately important to explore from the point of view of the Community Diabetes Advisory Group.

Two models were developed by including variables from each category that remained significant in multivariable regression analysis. Both models include age, sex, level of education and dyslipidemia. When included in the same model, chronic stress and negative impact of residential school both become non-significant thus loosing important information. Level of education, dyslipidemia and chronic stress all increase the odds of having higher perceptions of perceived control over the prevention of diabetes complications when controlling for each other and age and sex. The c-statistic for model A is 0.824 (95% CI: 0.740 – 0.907, p-value <0.001), and successfully predicts participant placement in the outcome response 75.5% of the time. Level of education, dyslipidemia and negative impact of residential school all increase the odds of having higher perceptions of perceived control over the prevention of diabetes complications when controlling for each other and age and sex. The c-statistic for model B is 0.818 (95% CI: 0.733 – 0.902, p-value <0.001), and successfully predicts participant placement in the outcome response 75.5% of the time.

Table 4.5.3 Logistic regression final model results of perceived control over the prevention of diabetic complications

Predictor	Odds Ratio	95% CI	P- value
Model A			
Age	1.011	0.966, 1.058	0.641
Sex	1.025	0.365, 2.881	0.963
≥ Grade 10	5.631	1.926, 16.459	0.002
Dyslipidemia	6.005	2.035, 17.715	0.001
Quite a bit or a lot of chronic stress	2.899	1.096, 7.672	0.032
Model B			
Age	0.990	0.940, 1.043	0.770
Sex	0.964	0.343, 2.706	0.944
≥ Grade 10	5.711	1.971, 16.551	0.001
Dyslipidemia	6.534	2.162, 19.744	0.001
Quite a bit or a lot of perceived negative impact from residential school	3.271	1.026, 10.421	0.045

Chapter 5

Discussion

Administering questionnaires directly to participants and obtaining feedback from the Community Diabetes Advisory Group (CDAG) has been invaluable to placing and explaining the results within the larger academic literature. Though the discussion of results includes linkages to academic literature, the discussion centers on interpretations of the results from what participants told me during the questionnaires and interpretations from CDAG. I presented my findings to the CDAG on June 5, 2012 and obtained feedback and member interpretations. After investigating CDAG interpretations with the literature, follow-up interviews were completed with specific members of CDAG by phone to ensure the discussion included in the thesis reflected community understandings and interpretations. Including community perspectives adds strength to this research because community members are experts in their own lived experiences.

This section opens with a discussion about knowledge translation throughout the research project and is organized by research objective. The discussion has increased emphasis on research questions 3 and 4 which focused on factors associated with prevention of diabetes and diabetes complications. Research question 3 and 4 are subdivided into a discussion about relationships between control and demographic variables, clinical markers, and stress/stressful life events. Select variables that were deemed important by CDAG, but were not significant in regression analyses are also discussed in the corresponding sections of the discussion.

5.1 Knowledge Translation

Knowledge translation with the Community Diabetes Advisory Group (CDAG) and the community occurred throughout data collection and analysis. On October 13, 2011 I attended my first CDAG meeting where I helped present preliminary results for the larger ongoing stress and diabetes study. I also met with, and presented to CDAG on December 7, 2011 about preliminary results specific to my project about perceived control and obtained feedback on which variables CDAG was interested in exploring. On June 5, 2012 I presented by final results to CDAG where I received their assistance with interpreting the results. A document containing key findings was also circulated to staff at the Health Centre involved in diabetes care for their input, and follow-up conversations occurred by telephone. A final report, which is an abbreviated form of my thesis with less emphasis on theory, was submitted to CDAG on August 8, 2012. CDAG members have also been invited to attend my thesis defense in Winnipeg, with transportation costs being covered by the larger study.

As part of this project I assisted in creating a personalized letter with each participants' personal health results (e.g., blood pressure, blood test). I also helped conduct a day-long workshop for the community held at 'The Complex' in Sandy Bay. I presented results from the study, explained how to interpret results from personalized letters given to every participant, and presented on how to use the Canada Food Guide. Throughout the study myself, and other research assistants kept a close relationship with the Sandy Bay radio station in order to keep the community informed about the study. On October 13, 2011 myself and Natalie Riediger partook in an on air interview about the research study.

While it is extremely important to engage in knowledge translation with the community, it is also important to present findings to the larger scientific community, which I have also done throughout my project. I presented preliminary results during an oral presentation at the First Nations, Métis and Inuit Research Symposium (December 1-2, 2011) at the Bannatyne campus at the University of Manitoba. I also conducted a poster presentation at the Canadian Health Student Research Forum on June 12, 2012, and an oral presentation at the National Gathering of Graduate Students in Aboriginal Health Research from June 22 – 25, 2012 at McGill University in Montreal.

5.2 Research Objectives 1 and 2

The first two research objectives of this study focused on determining the distribution of control variables. For all four measures of control a similar pattern emerged with approximately just over half of the sample indicating that they had quite a bit or a lot of control (life in general – 52.3%, physical health – 58.2%, prevention of diabetes – 52.2%, and prevention of diabetes complications – 57%).

Though not directly comparable, one control construct, mastery, has been included in the 1994/1995 Canadian National Population Survey and the 2000/2001 Canadian Community Health Survey (CCHS). Twenty-two percent of respondents of the CCHS survey had high mastery, where high mastery was defined as a score of 23 or more out of a possible 28, or in other words individuals who ranked at or greater than 82% of the possible total score (122). Only 17% of visible minorities in Canada and 18% of Manitobans were categorized as having high mastery (122). Limited research on beliefs of personal control has been conducted among Indigenous populations. In one study that investigated mastery in relation to diabetes in three First Nation communities in British

Columbia, the average scores, out of a maximum score of 5, were 3.9±0.6, 3.7±0.8, and 3.7±0.6 for the three communities or approximately 74-78% of the total possible score (94). The multidimensional health locus of control scale was used among American Indian participants of the Strong Heart study. Authors found that the average scores out of a possible 18 were 12.51 for Internal HLC score was 12.51 (69.5% of the total score), for Chance HLC 8.29 (46% of the total score), and 8.87 for Powerful Others HLC (49%). These findings mean that the American Indians in the study overall had moderate beliefs that they themselves could affect change (i.e., internal control). The 2008/10 Regional Health Survey (RHS) found that the levels of mastery reported among First Nations people were similar to the general population, though it did not provide specific numbers to support this claim in the report (97).

While approximately 50% of participants in the current study reported feelings of low control (responded none or a little bit), this is likely to reflect known understandings of diabetes etiology among First Nations people. A qualitative study in one Manitoba First Nation community talked about diabetes being caused by an external agent (35). If one thinks that diabetes is caused by an external agent it seems plausible that people wouldn't feel like they had any substantive personal influence on controlling the onset of diabetes or diabetes complications. In one study this external agent has been described as contaminated food (i.e., non-traditional foods brought to First Nation communities during colonization) (34). However, in the current study, most participants spoke of what people eat as being within individuals' control.

In a qualitative study amongst Indigenous Australians that investigated psychosocial mediators of health, including perceived control, the authors found that

individual control needed to be in balance with the community (123). This idea of balance with the community was also seen in a Native American community where women described that they could overcome problems by working together as a community (i.e., communal mastery), instead of only relying on themselves (57).

One's culture and experiences shape one's beliefs about how the world in which we live works, and if obtaining a desired outcome depends on one's own actions or not (124). Therefore, though approximately 50% of participants in the current study may be categorized as reporting "low-control" it may simply be a reflection of lived experiences with diabetes in the community. This idea is supported by studies in other Indigenous communities. For instance, in one study conducted in a Gila Indian community many participants believed that engaging in behaviors to prevent onset of complications would be futile, and 91% thought they would eventually get diabetes (92). In a separate study among American Indian women, participants described that the onset of diabetes was going to happen, often because diabetes was common in their families (93). Another qualitative study among low-income individuals in the U.S. suggested that individuals make fatalistic statements, indicative of low perceived control, to vocalize their understandings of limiting factors in their lives that influence their health (63). In addition, statements considered to be fatalistic always co-occurred with statements "endorsing the utility of behaviours for protecting health" (i.e., statements that could be considered high control) (63).

5.3 Research Objective 3: Perceptions of personal influence over diabetes prevention

5.3.1 Demographic variables and prevention of diabetes

When answering the questions, many people who explained the reasoning behind their response of quite a bit or a lot or control over preventing diabetes complications talked about individual control over one's actions. Most participants who gave an explanation with their response, regardless of how they answered the control questions, spoke about preventing diabetes by eating healthy (e.g., boiling potatoes instead of frying them), exercising, and/or maintaining a healthy weight. Even though some participants spoke about the importance of engaging in a healthy lifestyle, they still said they had little or no control over the prevention of diabetes and some cited the high prevalence of diabetes among their family as the reason. Results from this study show that, as the proportion of primary relatives with diabetes increases, there is a trend to have lower perceptions of control. Though this finding was not significant ($p = 0.072$) at alpha <0.05, the fact that a trend was evident should be considered an important finding given the high prevalence of diabetes in the community. This finding is in keeping with literature talking about diabetes running in the family (34), and how lived experiences are known to affect people's perceptions of their own risk (92) and therefore possibly their own ability to control the prevention of diabetes. In another study, American Indian women described knowing they would get diabetes because it was common in their families (93).

Age remained significant in each model, with perceptions of control over diabetes prevention increasing with age. Most previous studies investigating perceptions of control over health and life using various measures (e.g., primary/perceived control, self-efficacy, mastery, LOC) have found that people's perceptions of global control increase

as they age until approximately mid life (around 50 years old), and then begin to decrease (105). This pattern was not seen in the sample, with perceptions of control over diabetes prevention being higher as individuals aged. No interactions between age and other variables included in the models existed. In the context of Sandy Bay, this may be due to the high prevalence of diabetes within the community influencing individual's perceptions. The longer people go without being diagnosed with diabetes, or in other words the older you get with no diagnosis, the more likely they are to believe that they can successfully prevented the onset of diabetes, compared to younger individuals that still have many years of susceptibility ahead of them. In a previous study using mastery in a British Columbia First Nations community, men had an inverse U-shaped relationship with mastery with a peak at 25 years of age, while women had highest mastery between 15 and 24.9 years of age with decreasing mastery scored as they aged (95). Mastery scores in the B.C. First Nation community are not directly comparable to the current study because mastery is a global measure of control that is not specific to diabetes prevention, while perceived influence over diabetes prevention investigates perceived personal influence over the specific situation of preventing diabetes.

5.3.2 Clinical markers and prevention of diabetes

In the current study there was not a statistically significant relationship between perceptions of control over diabetes prevention and participants newly diagnosed glycemic status of impaired fasting glucose (IFG) or diabetes. Only one clinical biomarker, dyslipidemia, was positively associated with perceptions of high control over diabetes prevention (i.e., those with higher perceptions of control were those with

dyslipidemia). In this study individuals with dyslipidemia had HDL-cholesterol value ≤1.03 mmol/L for men and ≤1.30 mmol/L for women, and a triglyceride value of >1.7mmol/L. This specific type of lipid patterning is known to be associated with diabetes. One could hypothesize that people with better lipid values (high HDL-cholesterol and low triglycerides) would have higher perceptions of control because those who have higher perceptions of control may be more likely to engage in healthy lifestyle behaviors and thus having better lipid levels.

Only one other study has investigated lipid levels and perceptions of control (mastery) in an Indigenous community. This study was among three First Nation communities in British Columbia and the researchers found that normoglycemic participants who had low levels of HDL-cholesterol had greater mastery (125). In the B.C. study however, the authors suggested that the finding may be a chance finding that reflects a null-relationship between HDL-cholesterol and sense of control. However, this is not the first time that high mastery has been associated with adverse cardiovascular related measures. In one paper investigating mastery and coronary atherosclerosis among angiography patients, the authors reported that those with greater mastery had greater atherosclerosis (126). The fact that undesirable lipid patterns among Canadian First Nations populations was found to be associated in two distinct studies, using two different measures of control, suggests that there may be an underling biological process occurring in these individuals that warrants further investigation.

5.3.3 Stress and prevention of diabetes

Stressful life events (stressors) that remained significant in the combined model included hearing gossip about oneself and experiencing racism. Though both are correlated, and may be considered as types of violence, with those reporting experiencing more racism also experiencing hearing more gossip about themselves, both experiences operate at different levels. Racism can be considered a form of vertical violence, while gossip is a form of lateral or within-group violence. Both racism and gossip also both remained significant independent of each other in the combined model. Often participants would say they experienced racism outside the community in Winnipeg and Portage, while participants talked about gossip within the community. The research assistants, including myself, who administered the questionnaires, got the sense that people who reported experiencing gossip and racism were actively involved in events in and outside of the community. The fact that these people were involved may have increased their chances of experiencing these events.

Racism can be defined in many ways including "the beliefs, attitudes, institutional arrangements, and acts that tend to denigrate individuals or groups because of phenotypic characteristics or ethnic group affiliation" (127). Though there are many subtypes of racism, and the question given to participants was structured in such a way that participants could decide what racism meant to them, and which of their own experiences constituted racism.

The positive relationship between experiencing racism and feeling higher levels of perceived control over diabetes prevention was surprising given the substantive amount of research that supports the negative health impacts of racism on multiple

minority groups (128,129). CDAG likened the positive relationship between racism and control to individuals taking an "I'll show you" or "I'll prove you wrong" attitude, or coping technique, towards racism they experience and apply the attitude to "showing people that they can prevent diabetes". In the 2008/10 First Nations Regional Health Survey adults who said they had experienced racism sometime in the last year did not differ in mastery scores from those who did not report experiencing racism in the past year (97). The explanation offered by CDAG fits with some existing theories in the literature, specifically one that takes an ecological approach to explaining risk of hypertension among African Americans developed by Nancy Krieger. Krieger argues that there are multi-level pathways that link racial discrimination and biological processes throughout life with one being called "resistance to racial oppression" (130). She describes resistance as "individual and community resources and social movements to counter racism and to enhance dignity…" (130).

Another possible explanation of the phenomenon may be understood by examining the demographic characteristics of individuals who reported experiencing racism, specifically, individuals who had a grade 10 education or higher, were more likely to report experiencing racism. It is known that global perceptions of control are positively associated with higher levels of education.

Gossip is a significant source of stress for residents of Sandy Bay. Gossip was discussed at length during previous qualitative interviews, during administration of questionnaires in the current study, and by Health Centre staff. Gossip is a type of lateral violence and has been referred to as "internalized colonialism" (131). Lateral violence also includes jealously, bullying, shaming, social exclusion, family feuding,

organizational conflict, and physical violence (131). One definition provided by the Aboriginal and Torres Strait Islander Social Justice Commissioner in the 2011 Social Justice Report defines lateral violence as:

> *"The organized, harmful behaviors that we do to each other collectively as part of an oppressed group: within our families; within our organizations and; within our communities. When we are consistently oppressed we live with great fear and great anger and we often turn on those who are closest to us"* (131).

Lateral violence can be seen as a result of colonization because many Aboriginal people have been oppressed and live in marginalized situations where power may be difficult to exercise over anyone except your own people (132). Gregory Phillps goes further to explain gossip within Australian Aboriginal communities as a mechanism to help people feel powerful when they are in situations where they experience a lack of power or control (133). Power can be defined as "a person, group, or nation having great influence or control over others" (134). A lack of feeling powerful due to colonialism may result in low self-esteem because of internalization of oppressive experiences (133). The link between self-esteem and gossip is also discussed by Peter Randall, where he says gossip can cause communities to feel powerless and have reduced self-esteem (135). Isaias Harper, a Community Counselor/Therapist with the Sandy Bay Health Center believes that gossiping in the community has to do with both power and self-esteem, where individuals work to regain self-esteem and relative power when they are bullying others (personal communication, June 2012). Fern Beaulieu, the community Wellness and Education Services Coordinator at the Sandy Bay

Health Center also said that gossip is used in the community as a "control weapon" (personal communication, June 2012).

Why individuals who reported hearing more gossip said they had greater control over preventing diabetes may be explained by who hears gossip. Isaias Harper, says that from his experiences in Sandy Bay, those who are most likely to hear gossip also engage as a gossiper themselves (personal communication, June 2012). This may be supported by bullying literature in youth about "proactive victims," who are individuals who have been bullied who are more likely to be bullies themselves (136). It is plausible that bulling, including gossiping, after they have been bullied they may increase their sense of power or control because they are dominant over someone else. Further exploration between gossip, perceived control and health must occur within the community given the substantial impact of gossip reported by participants in the current study, as well as previous studies in the community.

5.4 Perceptions of personal influence over the prevention of diabetic complications

5.4.1 Demographic variables and prevention of diabetic complications

The only demographic factor that was significantly related to perceived control was level of education, with individuals having a grade 10 education or higher having significantly higher odds (approximately 5.5 times greater) of perceiving they have greater control over the prevention of diabetes complications. Some studies have found that individuals in the general population who have a higher level of education have increased perceptions of control (87,137,138). The 2008/10 RHS survey also found that

First Nations people with higher a level of education had higher perceptions of mastery (97). It is suggested in the literature that individuals with higher levels of education have more opportunities to influence events and exert control due to enhanced problem solving skills, work opportunities, and higher levels of income, and therefore perceive themselves to have more control than individuals who may have less chances of influencing events around them (137,139). Those who have a higher education may be more able to overcome certain situations because of increased problem solving skills, thus having past successes. In a qualitative study completed with a rural Aboriginal community in south-eastern Australia, the authors found that participants who described being confident due to previously experiencing success in some aspect of their life, also seemed to give people an increased "sense of control" (123).

5.4.2 Clinical markers and prevention of diabetic complications

Given the amount of literature indicating that individuals with diabetes who have high perceptions of control have better glycemic control (45,88,95,140,141) it was surprising that no statistically significant relationship existed between HbA1c or fasting glucose and level of control in this study population. However, a study that investigated perceived diabetes control using a Likert scale among 623 diabetic patients from Veterans Affairs health care system in the United States found that higher perceptions of diabetes control were negatively associated with HbA1c (i.e., had higher HbA1c levels) (141).

It may be that the relationship between HbA1c and perceived control is affected by treatment adherence (e.g., diet and actual medication use), which we were unable to

investigate during this study. Individuals indicated if they were prescribed medication, but it is unclear how well they were adhering to treatment recommendations. For individuals with diabetes, there was no relationship between perceptions of control and being prescribed medication for controlling blood glucose levels (e.g., metformin or glyburide) in the current study. A study among European Americans and Latinos with diabetes may support this: after taking into account diabetes management behaviors in regression analyses neither self-efficacy nor mastery was related to lower (i.e., better) HbA1c levels (142). A more recent meta-analyses looking at investigating the relationship between LOC and HbA1c did not find a statistically significant correlation (143). Again, indicating that only some measures of control may be related to HbA1c.

Similar to those without diabetes in the study, the odds of believing that you had high control over diabetes prevention were greater if you had dyslipidemia. This finding was contrary to one among three First Nations communities in British Columbia, where whose who had higher perceptions of mastery had higher (i.e., better) HDL-cholesterol levels (125). This difference may be due to the fact that mastery is a measure of global perceptions of control, and not specific to the prevention of diabetic complications. This finding also warrants further investigation.

5.4.3 Stress and prevention of diabetic complications

The relationship between perceiving that your life has been negatively impacted by residential school in a significant way and having high perceptions of your own ability to prevent diabetes complications was an unanticipated finding. Levels of perceived negative impact of residential school among participants were greater with older

participants, with a significant number of individuals in the over 50 group reporting significant negative impact. There were no differences between age groups amongst people who reported that they had quite a lot or a lot of chronic stress, even though the legacy of trauma from residential school is known to be a major stressor within the community based on previous qualitative interviews about stressful life events.

In order to understand why the relationship between residential school and perceptions of control may exist it is important to understand that perceived negative impact is a self-report measure that allowed participants to decide what "negative impact" meant to them. It can also be hypothesized that individuals who reported experiencing a greater negative impact from residential school were individuals who are aware of the effects due to the fact that they had been through or were in the process of healing from the legacy of residential school, thus exemplifying resiliency.

Resiliency can be described as "bouncing or springing back" from hardships and difficult experiences or being "self-confident" (144). In a recent study exploring trauma and suicide behavior amongst First Nations people the authors found that the older attendee group of residential schools (45+) was less likely to report a complex trauma history and seemed to have greater resiliency compared to younger age groups (145). Their findings also supported the existence of a "mentally healthy" residential school survivor cohort (145). In a separate report produced by the Aboriginal Healing Foundation the authors identified a study that supported the notion that "sense of control over one's life" as a protective factor in individuals developing resiliency (146,147). It is plausible that sense of control over preventing diabetic complications may have a similar relationship as perceived sense of control over life.

Participants who were previously diagnosed with diabetes and reported significant negative effects of residential school were also more likely to report engaging in traditional activities, visiting a traditional healer, and using traditional medicines and herbs to deal with stress. Though it is known that many individuals who attended residential school lost their ability to speak the language, and traditional values and culture, it may be that this cohort has tried to regain and reinforce culture and traditions, and in turn increased their perceptions of being able to prevent the onset of diabetic complications. By re-engaging with traditional practices individuals may be re-establishing balance and their connection to land, which loss of during colonization, is linked with an unbalanced life and diabetes (33,34). This is similar to a finding in the First Nations Regional Health Survey, where individuals who frequently participated in cultural events within their communities were more likely to have greater perceptions of global mastery (97).

These findings are also supported by interpretations from CDAG. Individuals on CDAG talked about resiliency and higher perceptions of control saying that individuals may be expressing a desire to prove that they can achieve goals and overcome adversities, in addition to attributing it to reinforcing positive self-esteem (i.e., a positive cultural identity). They also spoke to this when explaining the positive relationship between reporting increased chronic stress and having higher perceptions of control over preventing diabetic complications. Past successes may contribute to increasing individual's perceptions of control because they were previously able to "control"/overcome a specific situation. Fern Beaulieu, went further to say that many people express an attitude of "if I can survive this I can survive anything" and seem more

able to feel that they can control and overcome challenges in their lives such as the prevention of diabetic complications (personal communication, June 2012). In another model put forth by Wheaton, he hypothesizes that stressful life events force individuals to "mobilize resources" to reduce distress; and one of these resources is an increase in perceptions of personal control (148). These findings are in contrast with those from the 2008/10 RHS survey where those with lower psychological distress had higher scores on the mastery scale (97). It is likely that the questions about mastery in the RHS survey and control used in this study are assessing different perceptions of control. Mastery is a very general measure, whereas control over diabetes prevention is very specific. Also, people's perceptions of chronic stress and measures of psychological distress 'assigned' to them using various scales may be assessing different things.

Conversely, it is also possible that people who like feeling "in control", may be more likely to experience chronic stress if they live in an environment which makes it difficult to exert control because of a dysfunctional mismatch (53,91). The discrepancy between expectations for control and actual ability to control has been shown to produce high rates of physiological reactivity during stress experiments (149-151). This may be particularly relevant for members of the First Nations community with a high level of perceived control. In the context of Sandy Bay, individuals may feel like they are in control of the prevention of diabetic complications, but they are unable to engage in behaviors, such as exercising and eating fruits and vegetables, due to community's realities that are not conducive to preventing complications.

5.5 Limitations

This study employed a cross-sectional design thus preventing conclusions about any cause and effect relationships. The study also used many questions that relied on self-reported measures and participant perceptions that can be subject to biased reporting. As the main question about personal influence over diabetes prevention or the prevention of diabetic complications was developed specifically for this study, it is difficult to make direct comparisons with other studies employing different global measures of control such as self-efficacy or mastery. In addition, the findings of this study may not be generalisable to other populations as the questionnaire was based on peoples' experiences that may be community specific.

5.6 Strengths

The main strength of this research is that the study was conducted using a participatory action framework in partnership with the Sandy Bay Ojibway First Nation. This not only allowed the identification of important variables to investigate, but also helped tremendously in regard to interpretation of results. Being a part of the larger study also provided the researcher with the opportunity to spend 1-3 days a week in the community throughout the past year, and enabled her to be personally involved in primary data collection. Administering questionnaires to participants enabled the researcher to hear participants' reasons of answering certain ways. These comments, as well as those given by CDAG were integral to the interpretation of results.

Another strength lies in the questionnaire itself, as it was developed based on an ethnographic study in 2005 and previously piloted with 175 people in 2007/2008. This ensured that the questionnaire encompassed community experiences. The community

based sample of 520 participants is also large compared to some other community based studies and should be seen as a strength.

Chapter 6

Recommendations & Conclusions

6.1 Future Research Directions

A qualitative study to investigate community members' perceptions of personal control over the prevention of diabetes and diabetes complications would be beneficial in order to further explain and expand on the findings of this study. During a qualitative study, it may also be useful to investigate the perceived impact of communal perceptions of control on individual sense of control. Further investigation is also required about factors that affect perceptions of control at the family level (e.g., number of relatives with diabetes, caregivers, complications in the family, severity of illness of other family members). There is also a unique opportunity to investigate how individuals' perceptions of control over the prevention of diabetes and diabetes complications affect actual choices within the community. There is an ongoing study, with data collection slated for completion at the end of August, investigating dietary habits of community members. Are individuals who perceive that they have high control over diabetes prevention/the prevention of diabetic complications more likely to engage in behaviors (e.g., eating fruits and vegetables) to exert that control?

There is also the opportunity to look at perceptions of control over the prevention of diabetes and diabetes complications longitudinally, as my advisor Sharon Bruce has recently received an intervention planning grant and is working with the community to establish an intervention. Would individuals with higher perceptions of control over diabetes prevention be less likely to develop diabetes after the intervention is complete? Also, over time do perceptions of control change with changes in health status? As part of

this grant, questionnaires will also be developed and administered to younger age groups (eligible age group has yet to be determined), which would enable the investigation of perceptions of control over the prevention of diabetes across the lifespan.

It is important to approach other First Nations communities to investigate whether there are any differences between the respective communities in terms of associations with perceptions of high control. Are perceptions of control and factors that influence perceptions of control similar? Do communities served by DIP or NMU have higher perceptions of control over the prevention of diabetes and diabetes complications? Specifically, this information could be valuable to people at the Diabetes Integration Project who serve many First Nations communities in Manitoba and work to prevent the onset of diabetic complications. In addition, further investigation also needs to be done in regard to the relationship between control and dyslipidemia, and control and gossip.

6.2 Knowledge Translation Recommendations

Further consultations with CDAG specific to the findings in this study should occur when the results from the larger research project are discussed for inclusion into a proposed community intervention. Further to these consultations with CDAG, it will be important to receive additional interpretations from lay members of the community. During discussions with lay community members they should be asked what policy or programming they recommend to increase people's perceptions of control over the prevention of diabetes and diabetes complications.

6.3 Concluding Remarks

This participatory action community based study has provided further insight into factors associated with perceived control over diabetes prevention and the prevention of diabetic complications in a First Nation community. The findings showed that approximately half of the participants had low perceptions of their own ability to prevent diabetes or diabetes complications. However, people's low perceptions of their own control may reflect lived experiences and community understandings about diabetes. Factors associated with high perceptions of control over diabetes prevention included older age, dyslipidemia, experiencing racism, and hearing gossip. For those who already had diabetes, associations were found between beliefs in high controllability of preventing diabetic complications and dyslipidemia, high perceived negative impact of residential school, high self-reported chronic stress, and a level of education of grade 10 or higher. The explanations about these relationships provided by the Community Diabetes Advisory Group focused on the strength of individuals within the community, resilience, and overcoming difficult situations in life which contributes to increasing their perceptions of their own ability to influence outcomes related to diabetes.

This study establishes a base for further research in partnership with the community around perceptions of control over diabetes and diabetes prevention. It is our hope that with a greater understanding of factors that influence perceptions of control, along with ongoing research in the community, an intervention can be developed and implemented to reduce the burden of diabetes in Sandy Bay.

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Appendix

Table A1: Variables used in analysis

Variable	Definition	Code
Sex	Sex of participant	0 = Male 1 = Female
Age	Age of participant	Number of years
Age group	Age group of participant	1 = 18 – 24 years old 2 = 25 – 34 years old 3 = 35 – 49 years old 4 = 50 + years old
Years in community	How long the participant has lived in Sandy Bay Ojibway First Nation	1 = less than ½ of life 2 = more than ½ of life but not whole life 3 = whole life
Marital status	What is your current marital status?	0 = Not Married (never married, separated/divorced, widow/widower 1 = Married 2 = Prefer not to answer
Level of education	What is the highest level of education you have completed (graduated)?	0 = ≤ grade 9 education (includes life skills training) 1 = ≥ Grade 10 education (includes full or partial completion or college or university)
Employment status	Are you currently working for pay?	0 = No 1 = Yes
Aboriginal language	Can the participant have a conversation in an Aboriginal language?	0 = No and can't speak but understands (not fluent) 1 = Yes (fluent)
Self Rated Health	Compared with others your age, how would you describe your health?	0 = Poor or Fair 1 = Good, Very Good, or Excellent
Diabetes	Self-reported diabetes status	0 = No 1 = Yes
Diabetes duration	Number of years since diagnosis of diabetes	Continuous variable: Number of years
Family members with diabetes*	Does anyone in your family have diabetes?	0 = No & Unsure 1 = Yes

Variable	Definition	Code
# of primary relatives with diabetes*	Number of primary family members with diabetes including mother, father, sister(s), and brother(s)	Continuous variable: Number of family members
Proportion of primary relatives with diabetes*	Proportion of primary family members with diabetes including mother, father, sister(s), and brother(s). (# of parents with diabetes + # siblings with diabetes) / (total # of parents + siblings)	Continuous variable: Proportion
# of primary and secondary family members with diabetes*	Number of primary and secondary family members with diabetes including mother, father, sister(s), brother(s), and grandparent(s)	Continuous variable: Number of family members
Proportion of primary and secondary family members with diabetes*	Number of primary and secondary family members with diabetes including mother, father, sister(s), brother(s), and grandparent(s). (# of grandparents with diabetes + parents with diabetes + # siblings with diabetes) / (total # of grandparents + parents + siblings)	Continuous variable: Proportion
Hypertension	Presence of hypertension (includes self-report and newly diagnosed)	0 = No 1 = Yes
Arthritis	Presence of arthritis (self-report)	0 = No 1 = Yes
Heart problems	Presence of heart problems (self-report)	0 = No 1 = Yes
Stroke	History of stroke (self-report)	0 = No 1 = Yes
Number of chronic health conditions	Total number of chronic conditions experienced by the participant. Includes: diabetes, hypertension, dyslipidemia, obesity, and arthritis.	0 = No conditions present 0 = 0 conditions 1 = 1 chronic condition 2 = 2 chronic conditions 3 = 3 chronic conditions 4 = 4 or 5 chronic conditions
Current smoking status	Do you smoke now?	0 = No 1 = Yes
Ever smoked	Have you ever smoked cigarettes?	0 = No 1 = Yes

Variable	Definition	Code
Pack years	[(cigarettes smoked per day)/25 cigarettes] × (years as a smoker)**	Number
Mobility	Any of: (1) Difficulty walking 350 m; (2) Difficulty walking up/down 12+ steps; (3) Difficulty moving from one room to another on a single floor; or (4) Difficulty standing for more than 20 min.	0 = No 1 = Yes
Vision	Any of: (1) Difficulty seeing page even with glasses/contacts (if worn); or (2) Difficulty seeing face across room even With glasses/contacts (if worn)	0 = No 1 = Yes
BMI	Weight to height ratio	Number in kg/m^2
Dyslipidemia	Abnormal levels of triglycerides and HDL-cholesterol in the blood	0 = Normal lipid levels 1 = Dyslipidemia
HbA1c	Hemoglobin A1c – measure of glucose control over the last three months	Continuous variable
Fasting glucose	Fasting glucose level – measure of glucose control	Continuous variable
HbA1c controlled	Does the participant have their blood glucose levels controlled as per Health Center guidelines?	0 = Not controlled (HbA1c ≥9) 1 = Controlled (HbA1c < 9)
Diabetic complications	Did the participant self-report having any pre-existing diabetic complications (diabetes related amputation &/or feet problems (e.g., loss of protective sensation, infections, or poor circulation) &/or kidney problems &/or vision problems)?	0 = No 1 = Yes
Perceived acute stress	In the last month how often have you felt: (1) unable to control the important things in your life?; (2) nervous and "stressed"?; (3) confident about your ability to handle your personal problems?; (4) that things were going your way?; and (5) difficulties were piling up so high that you could not overcome them? Total score 5 -25 calculated using 5 questions each on a 5-point scale.	1 = Low acute stress (scores 5 – 12) 2 = High acute stress (scores 13 – 25)

Variable	Definition	Code
Perceived chronic stress	How much stress does the participant think they have experienced over their entire life?	1 = None & A Little Bit 2 = Quite a Bit & A Lot
Perceived chronic stress for your age	How much stress does the participant think they experienced over their entire life compared to others their age?	1 = None & A Little Bit 2 = Quite a Bit & A Lot
Negative impact of residential school	The perceived level negative impact of residential school on participants lives.	1 = None & A Little Bit 2 = Quite a Bit & A Lot
Not enough money	Has the participant not been able to afford things they needed in their life?	0 = always had enough money for the things they needed 1 = Didn't have enough money for something they needed sometime in their life
Run out of money	Has the participant run out of money before the end of the month?	0 = Never ran out of money before the end of the moth 1 = Ran out of money before the end of the month at some point in their life
Not enough money for food	Has the participant not had enough money to buy food for themselves or their family?	0 = Always had enough money to buy food 1 = Didn't have enough money to buy food at some point in their life
Hearing gossip about someone you care about	Has the participant reported hearing gossip about someone they care about at some point in their life?	0 = No 1 = Yes
Hearing gossip about yourself	Has the participant reported hearing gossip about themselves at some point in their life?	0 = No 1 = Yes
Experiencing racism	Has the participant reported experiencing racism at some point in their life?	0 = No 1 = Yes
Gambling problem	Has the participant reported having a gambling problem (e.g., VLT or bingo) at some point in their life?	0 = No 1 = Yes
Drinking problem	Has the participant reported having a drinking problem at some point in their life?	0 = No 1 = Chronic drinking problem 2 = Historical drinking problem

Variable	Definition	Code
Problem with drugs	Has the participant reported having a problem with drugs (illicit or prescription) at some point in their life?	0 = No 1 = Yes
Primary caretaker for family member with diabetes	If the participant has taken care of a family member with diabetes at some time in their life.	0 = No 1 = Yes
Perceived influence - Community	How much personal influence do participants think they have to make Sandy Bay a better place to live?	0 = Never 1 = Ever
Perceived control over health	How much personal influence participants feel they have over their physical health	1 = None & A Little Bit 2 = Quite a Bit & A Lot
Perceived control over life	How much personal influence participants feel they have over their lives in general	1 = None & A Little Bit 2 = Quite a Bit & A Lot
Perceived control over emotions	How much personal influence participants feel they have over their emotions	1 = None & A Little Bit 2 = Quite a Bit & A Lot
Perceived control over diabetes prevention	How much personal influence participants without a previous diagnosis with diabetes feel they have over preventing diabetes	1 = None & A Little Bit 2 = Quite a Bit & A Lot
Perceived control over the prevention of diabetes complications	How much personal influence participants with a previous diagnosis with diabetes feel they have over preventing diabetes	1 = None & A Little Bit 2 = Quite a Bit & A Lot

*****Includes full and half-blooded siblings from either biological parent.
******1 pack = 25 cigarettes

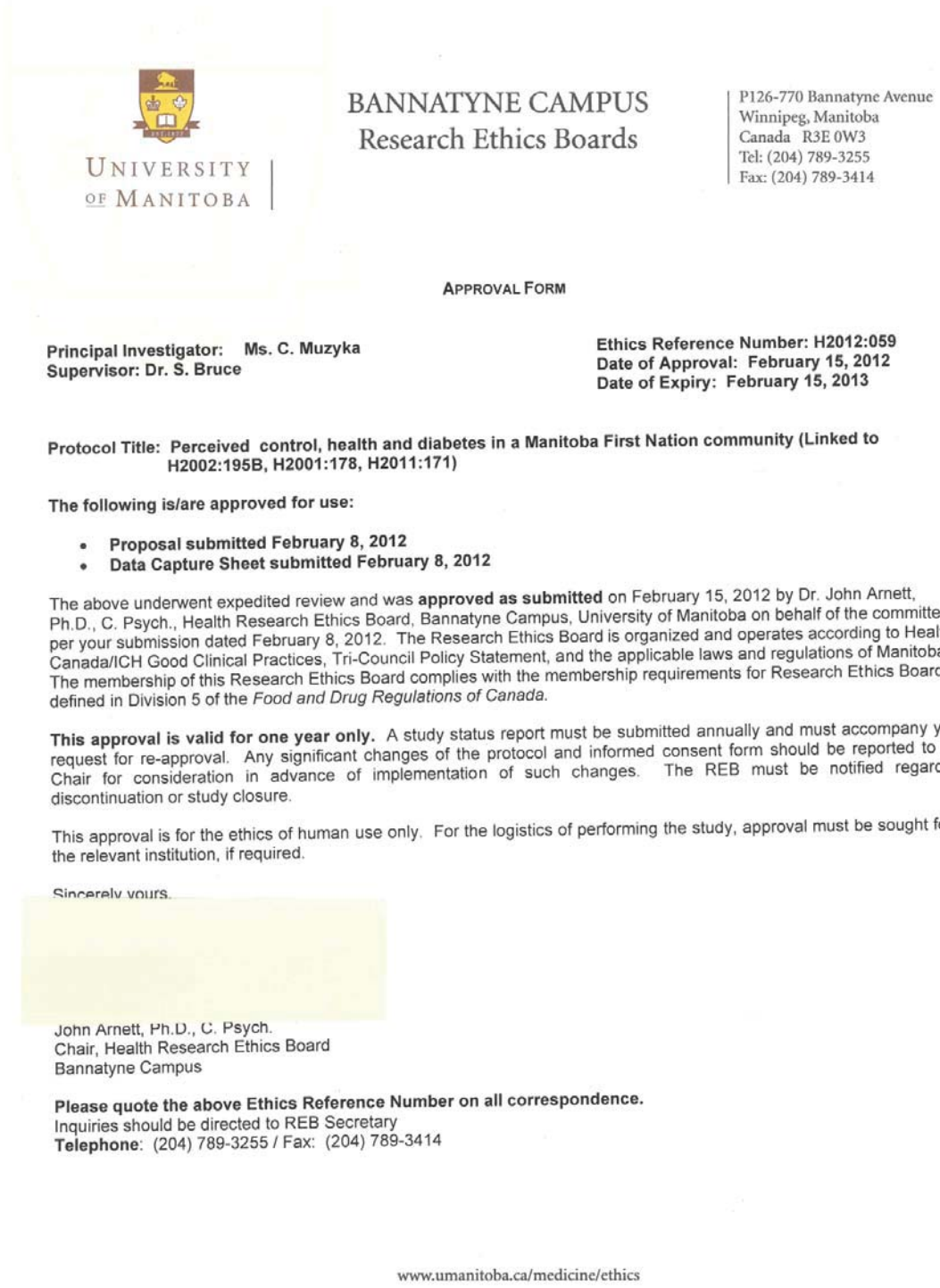
Table A2: Relationships with measures of control

Variable	Relationship	Measure of Control	Population	Sample Size	Study Design	Reference
Structural						
Racism	Racist experiences + relationship to HLOC powerful others (external HLOC)	HLOC	Black American Women	90	Cross-sectional	(152)
Housing Instability & Food Insecurity	Lack of stable place to stay – relationship with diabetes self-efficacy. Relationship mediated by food insecurity	Diabetes Self-Efficacy	18 years +, self-report diabetes, fluent in English/Spanish, ongoing medical care in San Francisco or Chicago, self-identify as Mexican American, African American, or non-Hispanic White.	711	Cross-sectional survey – data from Culture and Health Care (ICHC)	(153)
Community						
Neighbourhood SES	High proportions of neighbourhood unemployment and public social assistance are + associated with self-efficacy.	Self-efficacy	Adults that participated in the Americans Changing Lives Survey (1996)		Cross-sectional (administrative data)	(154)(155)
Family						
Social Support	More social support + association with self-efficacy	Diabetes Self-Efficacy	Korean women ages 40-65 years old with type-2 diabetes	154	Cross-sectional	(156)
Individual						
Individual SES	Low SES – associated with internal HLOC	HLOC	Adults (18-74) in the Caerphilly Health and Social Needs Survey	10,892	Cross-sectional	(155)
Relative Autonomy	- relationship between relative autonomy and external (chance) HLC (had an interaction with age). No significant relationship between internal, or external (powerful others) and relative autonomy	MHLOC	Adults of a health-promotion facility in Winnipeg	124	Longitudinal (1998 & 2002)	(72)
Cultural Landscape						
Ethnicity & Acculturation	More acculturated – relationship with fatalism (Most acculturated = Anglo, followed by African Americans, then Mexican Americans)	Fatalism	Adults living in San Antonio Texas	1,784	Cross-sectional	(157)

Table A3: Measures of control, cardiovascular disease and diabetes

Outcome	Relationship	Measure of Control	Population	Sample Size	Study Design	Ref.
HbA1c (medical regimen adherence)	External HLOC + relationship to HbA1c (better medication adherence measured by lower HbA1c levels)	Multidimensional HLOC	Low-income adults with type 2 diabetes for 1+ years, taking medication for diabetes for 6+months from Baton Rouge Louisiana and surrounding areas	109	Cross-sectional	(45)
CVD event	Low control beliefs were + associated with adverse cardiac events, independent of classic risk factors for CVD.	Mastery & Self-efficacy	Men and women 57 years or older residing in the Netherlands in 1993 who did not have heart disease.	3,888	Population-based prospective cohort	(158)
HbA1c (medical regimen adherence)	High self-efficacy + associated with adherence to diabetes treatment regimens	Self-efficacy	Adult diabetic outpatients	63	Longitudinal (2 months follow-up)	(159)
Medication regimen adherence (diabetes, HTN)	If patient and physician held similar control beliefs (external + external OR internal + internal) + relationship with med adherence	HLOC	Physicians at VA Iowa Medical Center and affiliated clinics and their patients with co-morbid diabetes and HTN with active medication prescriptions	246 patients 18 physicians	Cross-sectional	(10)
Metabolic control HbA1c	Diabetes fatalism - association with HbA1c control & decreased quality of life	Diabetes Fatalism	Adult patients with type 2 diabetes using primary care clinics in an academic medical center in South-eastern U.S.	216	Cross-sectional	(88)
Depression, Anxiety & HbA1c	High perceived control – relationship with depression, anxiety, and HbA1c.	Perceived Control	Adults with Type 2 diabetes (minimum diagnosis 6 months) from Diabetes Education Resources centers at 4 hospitals.	115	Cross-sectional	(140)
Depression & glycemic control (HbA1c)	Self-efficacy – correlated with depression and glycemic control for males (not found in females)	Self-efficacy	Adults with Type 2 diabetes who could speak English (*1/2 of sample made < $20,000/year, 62% education ≥grade 9)	163	Cross-sectional (with chart review)	(82)
Triglyceride & HDL-cholesterol	Mastery not related to triglyceride levels for participants with or without diabetes. Good HDL-cholesterol levels were positively associated with mastery for those with diabetes, but negatively associated with mastery for those without diabetes.	Mastery	First Nations adults participating in a diabetes screening program in B.C.	198	Cross-sectional	(125)

Figure A1: Bannatyne Campus Research Ethics Boards Approval Form



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APPROVAL FORM

Principal Investigator: Ms. C. Muzyka
Supervisor: Dr. S. Bruce

Ethics Reference Number: H2012:059
Date of Approval: February 15, 2012
Date of Expiry: February 15, 2013

Protocol Title: Perceived control, health and diabetes in a Manitoba First Nation community (Linked to H2002:195B, H2001:178, H2011:171)

The following is/are approved for use:

- **Proposal submitted February 8, 2012**
- **Data Capture Sheet submitted February 8, 2012**

The above underwent expedited review and was **approved as submitted** on February 15, 2012 by Dr. John Arnett, Ph.D., C. Psych., Health Research Ethics Board, Bannatyne Campus, University of Manitoba on behalf of the committee per your submission dated February 8, 2012. The Research Ethics Board is organized and operates according to Health Canada/ICH Good Clinical Practices, Tri-Council Policy Statement, and the applicable laws and regulations of Manitoba. The membership of this Research Ethics Board complies with the membership requirements for Research Ethics Boards defined in Division 5 of the *Food and Drug Regulations of Canada*.

This approval is valid for one year only. A study status report must be submitted annually and must accompany your request for re-approval. Any significant changes of the protocol and informed consent form should be reported to the Chair for consideration in advance of implementation of such changes. The REB must be notified regarding discontinuation or study closure.

This approval is for the ethics of human use only. For the logistics of performing the study, approval must be sought form the relevant institution, if required.

Sincerely yours,

John Arnett, Ph.D., C. Psych.
Chair, Health Research Ethics Board
Bannatyne Campus

Please quote the above Ethics Reference Number on all correspondence.
Inquiries should be directed to REB Secretary
Telephone: (204) 789-3255 / Fax: (204) 789-3414

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