

Running head: URBAN ABORIGINAL PEOPLES AND HYPERTENSION

**Urban Aboriginal Peoples' Health Beliefs and Adherence to Treatment for
Hypertension**

Thesis Submitted to the College of
Graduate Studies and Research
In Partial Fulfillment of the Requirements
for the Degree of Doctor of Philosophy
in the Department of Psychology
University of Saskatchewan
Saskatoon, SK

By Kristin Lorraine Calverley

© Kristin L. Calverley, July 2012. All Rights Reserved.

PERMISSION TO USE

In presenting this thesis/dissertation in partial fulfillment of the requirements for a Postgraduate degree from the University of Saskatchewan, I agree that the Libraries of this University may make it freely available for inspection. I further agree that permission for copying of this thesis/dissertation in any manner, in whole or in part, for scholarly purposes may be granted by the professor or professors who supervised my thesis/dissertation work or, in their absence, by the Head of the Department or the Dean of the College in which my thesis work was done. It is understood that any copying or publication or use of this thesis/dissertation or parts thereof for financial gain shall not be allowed without my written permission. It is also understood that due recognition shall be given to me and to the University of Saskatchewan in any scholarly use which may be made of any material in my thesis/dissertation.

Requests for permission to copy or to make other uses of materials in this thesis/dissertation in whole or part should be addressed to:

Head of Department
Department of Psychology
University of Saskatchewan
Saskatoon, Saskatchewan S7N 5A5
Canada

Abstract

Hypertension in Aboriginal peoples in Canada is on the rise, and the average age of onset is decreasing. Yet, little is presently known about how hypertension --diagnosis and treatment-- is perceived by Aboriginal persons currently diagnosed with the disease. The purpose of this thesis was to investigate urban Aboriginal persons' attitudes, beliefs, and approaches toward hypertension diagnosis and treatment recommendations. A second purpose was to engage with Aboriginal communities in action research to promote health and awareness of hypertension in a way that meets the communities' needs. I conducted the research from a critical theoretical perspective and action research methodology. Methods included individual interviews with 11 urban Aboriginal persons residing in Saskatoon who were diagnosed with hypertension by a health care provider, followed by a subsequent focus group with a sample of these interviewees. Being a non-Aboriginal researcher, I conducted this research with guidance from an Aboriginal advisory group who acted as a bridge between me and the community and helped to ensure ethical and cultural appropriateness of the study. I conducted thematic analyses of the interviews and focus group discussions. Findings revealed that overall the respondents adopted the dominant biomedical discourses for health. Specifically, respondents aligned with the individual responsibility framework for health rather than a broader-based view of responsibility. Additionally, respondents demonstrated their knowledge and expertise of biomedical knowledge, despite the persistence of perceived power imbalances and colonial exchanges within health care encounters with Aboriginal patients. Finally, respondents also tended to align with a biomedical approach to the treatment of hypertension, including the use of antihypertensive medications and lifestyle modifications. My analyses also demonstrated that tremendous variability in beliefs and orientations toward health existed in my sample of urban Aboriginal persons. The findings from

the present research suggest that such diversity is crucial to consider during health care encounters, as a single approach will not suit the needs of all Aboriginal patients. Although the adoption of biomedical discourses remains prominent, future interventions need to consider the role of macro-level forces on health. Dissemination included a newspaper article, executive summary, and discussions with Aboriginal health policy analysts.

Table of Contents

	<u>Page</u>
Permission to Use	i
Abstract	ii
Table of Contents.....	iv
List of Tables	vii
List of Figures.....	viii
Acknowledgements	ix
Chapter 1: Introduction	1
Part One: Health Information	1
Hypertension: Causes and Effects	2
Stress	7
Ethnic and Cultural Research on Hypertension	8
Aboriginal Health	11
Current health statistics	15
Local population.....	17
Trend toward urbanization	18
Hypertension and Aboriginal People	19
Social Determinants of Health	20
Income and income distribution	23
Unemployment and job security	24
Education	24
Housing	25
Aboriginal status	25
Aboriginal Determinants of Health	26
Colonization	27
Globalization	27
Migration	27
Cultural continuity	29
Territory	29
Access	29
Poverty	29
Self-determination	31
Broader Understandings of Health	31
Knowledge Translation and Policy	32
Part Two: Adherence and Treatment Issues	35
Theories of adherence	36
Adherence and Hypertension	40
Ethnic and cultural minorities, adherence, and hypertension	42
Aboriginal Peoples and Adherence	43
Aboriginal Worldviews of Health	46
Conclusion	49
Chapter 2: Methods and Procedures	52
Primary Issue	52
Purposes of the Study	52

Defining communities	53
Research Questions	53
Rationale for Qualitative Research.....	53
Epistemological Position	55
Theoretical Perspective	57
Methodology	61
Participatory action research	61
Action research	63
Formation of the Aboriginal advisory group	68
Standards of quality	73
Methods	74
Recruitment process	75
Respondents	78
<i>Roles I had with respondents</i>	81
Interviews	81
Focus group	84
Reflective Positioning.....	88
Ethics for Research Involving Aboriginal Peoples	92
OCAP principles	92
The Royal Commission on Aboriginal Peoples and the Aboriginal Action Plan.....	94
Data Analysis	96
Thematic analysis	96
Transcription	97
Phases of analysis	98
Chapter 3: The Morality of Health: Who is Responsible for Being Healthy?	102
Introduction	102
Historical Progression of Morality and Health	103
Individual versus Shared Responsibility for Health	107
Data Analysis	108
Self-determination	112
Lack of agency	120
Challenging individual responsibility.....	126
Reflexivity and Interview Questions	128
Conclusion	129
Chapter 4: Lay versus Expert Knowledge	130
Introduction	130
Data Analysis	133
Language	134
Demonstrations of lay knowledge	137
Expert patient	145
Power	149
Colonialism in health care	154
Conclusion	161
Chapter 5: Hypertension Treatment: Issues and Implications	164

Introduction	164
Data Analysis	165
Part One: Adherence Issues	167
Alignment with treatment recommendations	169
Episodic medication-taking for the treatment of hypertension	171
Ambivalence toward taking medications	174
Resistance to treatment	175
Medication as personal weakness	176
Medication as a colonial agent	177
Addictions	179
Part Two: Other Worldviews of Health	181
Medicine keepers	182
Medicine wheel	187
Emotional balance	191
Conclusion	195
Chapter 6: Action Research	
Action Research: Suggestions for Improvement	197
Taking Action	200
Chapter 7: Discussion	
Summary of Findings	204
Implications	209
Possibilities for Future Research- Strengths and Limitations of the Present Research	211
Importance of the Findings	221
References	223
Appendix A	Student/Community Partnership Agreement
Appendix B	Recruitment poster
Appendix C	Interview Question Guide
Appendix D	Aboriginal advisory group Letter of Support
Appendix E	REB Study Approval Form
Appendix F	Consent Form
Appendix G	Transcript Release Form
Appendix H	Action Suggestions
Appendix I	Focus Group Consent Form
Appendix J	Confidentiality Clause (Focus Group Respondents)
Appendix K	Confidentiality Clause (Aboriginal Advisory Group)
Appendix L	Analysis Codes
Appendix M	Themes
Appendix N	Indigenous Times article
Appendix O	EXECUTIVE SUMMARY

List of Tables

	<u>Page</u>
Table 1. <i>Health Conditions</i>	13
Table 2. <i>Education, Work Status, and Income (% of population)</i>	16

List of Figures

	<u>Page</u>
Figure 1. Age-Sex-Specific and Age-Adjusted Prevalence of Self-Reported Hypertension %	22
Figure 2. Analytic Codes of Sub-Theme: Self-Determination	109
Figure 3. Analytic Codes of Sub-Theme: Lack of Agency	111
Figure 4. Lay Versus Expert Knowledge Thematic Analysis.....	135
Figure 5. Adherence to Hypertension Treatment	166
Figure 6. Treatment Worldview	168

Acknowledgements

Writing this thesis has been life-changing. I owe special thanks to many people who supported my journey and contributed to the completion of this work.

First and foremost, thank you to the participants and Aboriginal communities of Saskatoon without whom this work would not have been possible. I extend my sincerest gratitude to the Aboriginal advisory group, Dr. Raven Sinclair, Ms. Sherry Pooyak, Elder Danny Musqua, and Mr. Jason Albert. Thank you for your guidance throughout the research.

I also acknowledge deepest gratitude to my academic community for fostering my development as a researcher and a psychologist. In particular, I would like to wholeheartedly thank my research supervisor, Dr. Linda McMullen for her mentorship, support, and inspiration. I also thank my committee members, Drs. Karen Lawson, Ulrich Teucher, Rose Roberts, and Gerri Dickson, for their guidance and expertise, and my editor, Dr. Sayma Malik who contributed to the grammar and clarity of the analysis.

Thank you to my family for all their encouragement and support over the years. I am especially grateful to the qualitative research team and to my colleagues Drs. Rebecca Boehm, Selina Zaluski, and Alissa Levi along with Jeff Letourneau, Cara Spence, Darren Wagner, and Allison Henderson for their relentless support and sanity.

I would also like to acknowledge financial support I received during my studies: the University of Saskatchewan Department of Psychology Graduate Teaching Fellowship, the College of Graduate Studies and Research Dean's Scholarship and the Canadian Institutes for Health Research-Regional Partnership Program.

Chapter 1: Introduction

“If you think you are too small to make a difference, try sleeping in a closed room with a mosquito” – African Proverb

In this dissertation, I investigate the beliefs about health, illness, and adherence to treatment recommendations implicated in the diagnosis of hypertension in Canadian Aboriginal peoples. In the introduction, I provide a summary of the causes, risk factors, and consequences of hypertension. This review includes information on the current health status of Aboriginal peoples in Canada and considers the role of culture and race in hypertension.

Following this review, I explore adherence to treatment recommendations for hypertension. From this literature review, I conclude that there is a lack of knowledge or understanding about how hypertension and treatment recommendations are perceived by Canadian Aboriginal peoples. In addition, the majority of Canadian Aboriginal peoples now reside in urban centres, yet most Aboriginal health research has been conducted in rural and reserve settings. As such, the present research is motivated by the position that more information is needed to foster and promote health in these understudied communities. In this dissertation, I investigate the beliefs about hypertension and treatment recommendations in Aboriginal peoples in Saskatoon through a series of open-ended interviews, culminating in action research in collaboration with members of Saskatoon’s Aboriginal communities.

Part One: Health Information

In this section, I have included relevant information about the nature of hypertension: defining and diagnostic criteria, prevalence, relation to other conditions, causal factors, and methods of treatment. I also present literature about hypertension cross-culturally. Following this, I explore pertinent health information for Aboriginal peoples of Canada, and more

specifically for the local Aboriginal populations of the province of Saskatchewan. Subsequently, I present literature of a broader understanding of health, namely the social and Aboriginal determinants of health.

Hypertension: Causes and Effects

Hypertension is described by the World Health Organization (WHO) as the world's "leading risk of death, affecting 13% of the global population" (World Health Organization [WHO], 2009). Also known as high blood pressure, hypertension is a major risk factor for heart disease, and presently affects approximately 6 million Canadians (Heart & Stroke Foundation of Canada [HSFC], 2011b; Public Health Agency of Canada [PHAC], 2010). As cardiovascular disease (CVD), or heart disease, is the leading cause of death for over one-third of all Canadians, such health statistics highlight a pivotal area for further inquiry (HSFC, 2010). The economic burden of CVD in Canada was estimated at about 20 billion Canadian dollars (\$18,000/per person) in 1999 (Health Canada, 1998; HSFC, 1999). Despite a lack of recent data, it is projected that costs have since soared as Canadians continue to age (HSFC, 2006). Likewise, the number of people living with CVD is also expected to increase (HSFC, 2006). This prediction has significant consequences for the Canadian health system—for its infrastructure, resources, and financial sustainability-- and therefore warrants immediate attention. Likewise, hypertension is the leading risk for stroke, which remains one of the leading causes of death in Canada (HSFC, 2011b). When hypertension is managed properly, the risk of stroke is reduced by 40% (HSFC, 2011a).

Hypertension is a chronic condition resulting from excessive and prolonged pressure in the walls of the blood vessels as blood circulates or when cardiac output is excessive and increased blood flow puts an overload of pressure on the arterial walls (The Canadian

Hypertension Society [CHS], 2011; PHAC, 2010). When the correlation between cardiac output and peripheral resistance becomes unbalanced, the body can progress to a hypertensive state (Kershaw, 2010). Normal blood pressure, measured in millimetres of mercury (mm HG), is ongoing equilibrium between cardiac output (measured as systolic blood pressure [SPB]) and peripheral vascular resistance (measured as diastolic blood pressure [DBP]), ranging from SBP 90-120mm HG and DBP 60-80mm HG (Beevers, Lip, & O'Brien, 2001; HSFC, 2011a). Blood pressure's role in the body is to enhance tissue perfusion and to balance sodium and water levels in the body (Karppanen & Mervaala, 2006; Kershaw, 2010).

Hypertension is often defined as SBP pressure ≥ 140 mm HG or DBP ≥ 90 mm HG (HSFC, 2011a). Blood pressure levels ranging from 130/85mm HG to 139/85mm HG are considered "high normal" blood pressure, or pre-hypertension. In recent years, it has been determined that pre-hypertension also requires aggressive treatment consisting of lifestyle modifications as the risk of progressing to full hypertension within four years is greater than 60%; annual follow up is crucial for such individuals (Canadian Hypertension Education Program [CHEP], 2012; HSFC 2011a).

Hypertension is not the result of one elevated blood pressure measurement reading. Instead, several standardized readings are required over multiple days in order to ensure that the blood pressure level is consistently elevated (HSFC, 2011a). Blood pressure naturally fluctuates with such activities as running up a flight of stairs or lying down and relaxing. However, a phenomenon called white coat hypertension occurs when a patient's blood pressure rises only while in the presence of a health care professional (CHEP, 2012). As such, automated blood pressure measurement devices for use at home (or in pharmacies) are available and encouraged on such occasions.

Urban Aboriginal Peoples and Hypertension

Because uncomplicated hypertension is virtually undetectable, it is often referred to as the “silent killer” in that, left untreated, will progress to CVD, heart attack, or stroke (Wilkins et al., 2010). Consequently, hypertension may go undetected for years, leading to greater risks of complications or CVD.

Approximately 20% of Canadians aged 18-79 years are hypertensive, 20% are pre-hypertensive and 90% of our population will become hypertensive if they live to be 80 years of age or greater (HSFC, 2011b; Vasan et al., 2002; Wilkins et al., 2010). However, with the increasing prevalence rates hypertension is expected to affect 25% more Canadians by 2012 than in 2006 (PHAC, 2010). The physician, pharmaceutical, and laboratory costs of hypertension are approximately \$2.33 billion Canadian dollars/year (Joffres, Campbell, Manns, & Tu, 2007). Approximately 35% of all Canadians with hypertension are unaware of it or do not manage it properly (Wilkins et al., 2010). Hypertension is, then, a serious disease that warrants intervention and prevention efforts.

Hypertension has been shown to double or triple a person’s risk for cardiovascular illnesses and, according to the Canadian Hypertension Education Program (CHEP), 91% of individuals with hypertension have at least one risk cardiovascular risk factor (CHEP, 2012). Hypertension is also a major risk factor for congestive heart failure, dyslipidemia (high lipid count), coronary artery disease, atrial fibrillation (an irregular and often rapid heartbeat), glucose intolerance, insulin resistance, renal failure or disease, erectile dysfunction, and diabetes (CHEP, 2012; HSFC, 2003; PHAC, 2010). Left untreated, hypertension can result in vascular cognitive impairment, Alzheimer’s disease, and other dementias especially when the onset of hypertension occurs at a younger age (Campbell, Petrella, & Kaczorowski, 2006; CHEP, 2012; Saxby, Harrington, McKeith, Wesnes, & Ford, 2003). When blood vessels in the brain are exposed to

increased pressure, vascular deterioration including white matter damage, lacunae, and disconnections in cortical regions can ensue (Nagai, Hoshide & Kario, 2010). Overall, prolonged elevations of blood pressure lead to various forms of vascular pathology, relating to the onset of all forms of dementia (Nagai et al., 2010).

Not only is hypertension a risk-factor for diabetes and kidney disease, but the reverse is also true. Specifically, individuals with diabetes are three times more likely to be hypertensive than those without diabetes (PHAC, 2010). Therefore, it is important for individuals with diabetes to maintain a healthy blood pressure as all risk factors significantly increase. Compared to mortality rates for hypertension, having both diabetes and hypertension doubles the risk of death (PHAC, 2010). For individuals with diabetes, a diagnosis of hypertension is given at the “prehypertension” measurement of 130/88mm HG rather than the standard 140/90mm HG (HSFC, 2011a; Wilkins et al., 2010). Similarly, upon diagnosis of hypertension, kidney function needs to be closely evaluated. Due to the severity of the disease if left untreated, early detection of hypertension is crucial.

Demographic risk factors for hypertension include: age (onset typically occurs after age 35), ethnicity (African Americans and Aboriginal peoples have higher rates), family history of hypertension, and sex (affects more men than women until approximately age 55, then women have higher rates post-menopause) (HSFC, 1999, 2002; PHAC, 2010; Wilkins et al., 2010).

Only 5% of cases are considered secondary hypertension, meaning they have an evident and direct causal agent; the other 95% of cases have mixed or unknown etiology (Daniel & Rotimi, 2003). Genetic heritability for essential hypertension accounts for approximately 30%; however, a specific gene for the disease has not been located at this time (HSFC, 1999). Known

causes for secondary hypertension include renal disease, adrenal glands tumors, narrowing of the aorta, or metabolic syndrome.

When the etiology is unknown, it is referred to as essential (or primary) hypertension. Essential hypertension is often a combination of many factors including sedentary lifestyles, poor diet, obesity, high alcohol or sodium intake, excessive caffeine consumption, diabetes, stress, and smoking (CHEP, 2012; HSFC, 2011a). The majority of these risk factors are both preventable and modifiable.

Best treatment practices for hypertension generally consist of a combination of lifestyle modifications and pharmacological treatment (CHEP, 2012). In terms of lifestyle modifications, the Canadian Heart Health Survey, in partnership with Health Canada, identified that reducing individual sodium intake by 1840mg/day was a major priority in counteracting hypertension (Joffres et al., 2007). Such reductions would decrease hypertension prevalence rates by 30%, and would save \$430 million Canadian dollars/year in pharmaceutical costs and \$108 million Canadian dollars/year in physician and laboratory costs (Joffres et al., 2007; Penz, Joffres, & Campbell, 2008). Notably, such dietary reductions in sodium would also translate into five million fewer physician encounters per year relating to hypertension (CHEP, 2012). Target sodium consumption is 1200- 1500mg/day (the equivalent of approximately half a tablespoon of table salt) which is challenging as 75% of sodium consumed is from processed, canned, or pre-packaged foods (CHEP, 2012; HSFC, 2011b). Presently, Canadian consumption levels triple the recommended intake (CHEP, 2012; Penz et al., 2008).

Additional lifestyle modifications indicated by CHEP (2012) include eliminating smoking and consuming a healthy and nutritious diet in accordance with the recommendations of the Canada's Food Guide and dietary approaches to stopping hypertension (or DASH diet)

(HSFC, 2011a). The DASH diet resembles the Canada Food Guide's recommendation however it emphasizes increasing potassium, magnesium, and calcium while simultaneously decreasing sodium intake (HSFC, 2011a). Physical activity should be increased to at least 30 minutes of moderate intensity exercise per day 4-7 times weekly. Moreover, reducing and maintaining a healthy body mass index of < 25 further indicated predominantly by a waist circumference for men $< 102\text{cm}$ and women $< 88\text{cm}$. Alcohol consumption should be low-risk. Specifically, consumption should be no greater than two drinks per day and no more than 14 drinks per week (males) or nine drinks per week (females). Finally, to adequately manage stress, CHEP (2012) recommends behaviour modification and cognitive behaviour therapy (CBT) with a focus on relaxation strategies. Adhering to these lifestyle modifications enhances overall health through both the treatment of hypertension and the prevention of additional cardiovascular and related illnesses.

Pharmaceutical treatment is individualized and may consist of angiotensin-converting enzyme [ACE] inhibitors, renin inhibitors, angiotensin-receptor blockers [ARBs], beta-blockers, diuretics, or long-acting calcium channel blockers (CHEP, 2012). Although dual combination therapy is sometimes required, physicians are encouraged to strive for single pill combination treatment (CHEP, 2012). A primary focus of both lifestyle modification and pharmaceutical treatment remains on reducing further cardiovascular risk and protecting the vascular system from further decline (CHEP, 2012).

Stress. Although the national reports and resource documents inconsistently mention stress as a risk factor for hypertension, the evidence for the links between stress and cardiovascular functioning are clear. When humans cognitively appraise a stress or threat, the sympathetic nervous system responds by increasing heart rate, blood pressure, and galvanic skin

response. Increased stress results in enhanced cardiac output, vasoconstriction, and arterial pressure elevation (Yan et al., 2003).

Though acute stress activates the hypothalamic pituitary-adrenal (HPA) axis, the body typically recovers quickly and restores homeostasis. Research evidence suggests that it is chronic, rather than acute, stress that is more strongly implicated in the onset of hypertension, as the degrading effect on blood vessels is pronounced. In addition, with prolonged activation of the HPA axis, chronic inflammation can occur, leading to increased abdominal obesity (Kershaw, 2010; Pickering, 2007).

Stress can lead to hypertension risk factors, such as obesity, through such physical responses to the inflammatory response, or it can lead people to engage in poor lifestyle choices, e.g., poor eating habits, alcohol consumption, smoking (Kershaw, 2010). Similarly, as hypertension is linked to poverty, chronic social determinants such as unemployment, financial insecurity, and substandard housing are daily stressors for those burdened by hypertension.

Of note, both CHEP and HSFC recommend stress management (through CBT or relaxation techniques) as a way to prevent and treat hypertension (CHEP, 2012). Nonetheless, the vast majority of interventions and research highlighting advances in hypertension treatment recommendations neglect to address the role of stress and its management. This lack of recognition in the public arena of the impact of stress on heart health is glaring and highlights a major gap in treatment protocols.

Ethnic and Cultural Research on Hypertension

The literature on hypertension has taken culture, race, and ethnicity into account as potential risk factors; yet, the vast majority of hypertension research studies have tended to

neglect women, ethnic minorities, and vulnerable people in general.¹ For instance, the Framingham heart study -- one of the largest, longitudinal studies examining CVD development and risk factors in a healthy group of 5209 people since 1948 -- failed to include race as a moderating variable as the majority of the respondents were Caucasian (LaVeist, 2005; Vasan et al., 2002). According to the research literature, being part of an ethnic minority group and having lower social-economic status (SES) are both risk factors in the development of CVD and hypertension (HSFC, 1999; PHAC, 2004). Likewise, low SES and ethnic minority status remain highly correlated (LaVeist, 2005; Raphael, 2009).

Of the literature that includes ethnicity and its relation to blood pressure, the majority of this research has involved African Americans who have demonstrated the greatest risk for developing hypertension compared to all other ethnic groups (Bosworth et al., 2008; Kershaw, 2010; Nesbitt, 2005). This increased risk persists even after controlling for SES and common risk factors. The persistent, elevated rate of hypertension among African Americans is complex. Recent findings have demonstrated “increased salt sensitivity, lower levels of plasma renin, and higher peripheral vascular resistance” in African Americans (Nesbitt, 2005, p.244). Nevertheless, the theory of African Americans having a greater propensity for cardiovascular reactivity is challenged by other evidence supporting the role of socioeconomic, diet, medication nonadherence, and geographic risk factors in African Americans with hypertension (Bosworth et al., 2008; Jonas & Lando, 2000; Kershaw, 2010). Empirical support for both sides of the debate has been demonstrated. Moreover, African American women in particular appear to be at the

¹ For the purposes of the present study, culture is defined as the set of shared attitudes, values, goals, and practices that characterizes an institution, organization, or group of individuals; race is defined as a local geographic or global human population distinguished as a more or less distinct group by genetically transmitted physical characteristics; and ethnicity is defined as relating to large groups of people classed according to common racial, national, tribal, religious, linguistic, or cultural origin or background. Of note, these terms are defined by the Merriam-Webster dictionary rather than a medical reference as they are often contested.

highest risk. It remains impossible to pinpoint one direct causal agent for the increased rates of essential hypertension in African Americans.

Other ethnic groups also demonstrate high rates of hypertension as compared to Caucasians. For instance, Korean Americans have higher rates of hypertension compared to the general American population (32% versus 24%) (Kim, Kim, Juon, & Hill, 2000). Likewise, Asian Americans, in general, have higher rates of hypertension as they acculturate to North American living, whereas rates of hypertension are reduced and insignificant when traditional lifestyles are maintained post-immigration (Kaplan, Chang, Newsom, & McFarland, 2002). Kaplan et al. (2002) posited that with acculturation comes a change in diet consisting of an increase in sodium and fat content as well as reduced physical activity levels. In Chinese American immigrants, women over the age of 45 had higher systolic blood pressure than men, leading to greater risk for stroke (Li, Wallhagen, & Froelicher, 2007). Further, Hispanic Americans are described as having lower awareness of hypertension than either African Americans or the majority population; such reduced awareness is related to higher prevalence rates (Sudano & Baker, 2001).

In contrast, sometimes patients hold valuable insight into their conditions. A study involving African Americans and Latinos found that most people diagnosed with hypertension saw a direct connection between poor diet and the onset of their illness (Horowitz, Tuzzio, Rojas, Monteith, & Sisk, 2004). Overall, the respondents found that modifying their diet by reducing pork, salt, and alcohol consumption and increasing fruits, vegetables, and garlic in their diets was an effective way to manage hypertension.

Much less is known about hypertension in most ethnic groups in Canada. According to the Heart and Stroke Foundation of Canada, the highest rates (15.2%) of hypertension among

ethnic groups in Canada were observed in the Eastern European (broadly defined) population (HSFC, 2003). The average Canadian rate of hypertension in 2011 was 20% and available data from 2010 suggests that hypertension rates in Chinese Canadians and South Asians were 11%, and 10% respectively (HSFC, 2003; 2011a).

Unfortunately, the majority of cross-cultural research on hypertension is epidemiological, and involves comparing ethnic minority groups to the majority. Such research rarely examines within group differences and variability. In contrast, Kershaw (2010) found that rates of hypertension in African Americans vary depending on the geographic region and degree of segregation within neighbourhoods in the USA, and individuals born in southern states had higher rates of hypertension than those from the North. As a result, Kershaw concluded that sub-groups of African Americans exist and variability is often mediated by macro-level factors such as access to resources and poverty. While it is important to examine how hypertension is distributed demographically, macro-level factors that affect ethnic groups must be included in analyses of health disparity.

Aboriginal Health

Aboriginal peoples of Canada are identified as those with First Nations, Métis, or Inuit heritage. There are considerable nation-wide differences in culture, traditions, and language among Canada's Aboriginal people. The most recent Canadian census (2006) noted that 4% of the nation's population self-reported as Aboriginal (Statistics Canada, 2006). As Canadian census information is rigidly based on individuals being home on a particular day or living in a place for a specific amount of time, these percentages are deemed to be underestimates of the actual population size. Similarly, the vast majority of archived Canadian Aboriginal health data is collected from "Registered Indians" and is therefore limited and an underestimate of existing

conditions (CIHI, 2004). Registered Indians, also referred to as Status Indians, are First Nations people who are granted special rights and benefits by the Canadian government, and have their name on the Indian register (CIHI, 2004).

A recent Canadian report on health disparities noted that, even though many Canadians are extremely healthy, many are not (PHAC, 2004). Health status is unequally distributed (see Table 1) and the negative consequences of health disparities and social determinants of health primarily affect the lowest 20% of the SES scale and Aboriginal peoples (PHAC, 2004). In this table, various health conditions are displayed, divided into the following five groups: Aboriginal peoples (overall and non-reserve); Canada (overall and Non-Aboriginal); Inuit (overall and Nunavut); and Métis/Métis and non-status Indian. See footnote for detailed explanation of the data sources which inform the sub-scripts in Table 1. Further, the first two rows of data reflect the percentage of the population that is overweight or obese. Following this, four chronic diseases are expressed in percentage of prevalence within the population whereas two infectious diseases (tuberculosis and chlamydia) are displayed as rate per 100,000/yr. Finally smoking rates are described in % of population engaging in this health behaviour.

The data in Table 1 reveal that, overall, Aboriginal peoples' health is worse than the non-Aboriginal and overall Canadian population. The statistics demonstrate that Aboriginal people have higher rates of obesity, chronic and infectious diseases, and smoking. When the data are separated into First Nations, Inuit, and Métis peoples, it is evident that First Nations people have the worst health rates overall, followed by Métis people. Inuit populations surveyed have the best rates of all three groups of Aboriginal peoples, at times comparable to the overall Canadian

Urban Aboriginal Peoples and Hypertension

Table 1

Health Conditions

	Aboriginal Peoples _c (non-reserve _{a,b})	Canada _{d, e/} Non-Aboriginal _{a, c}	First Nations On-reserve _{d, e} Off-reserve _b Status Indian _c	Inuit _{b, c} (Nunavut _f)	Métis _b , Métis & Non-status Indian _c
Body Weight/BMI (% of population)					
Overweight	34 _a	32 _a	35 _b	35 _b	35 _b
Obesity	25 _a	14 _a	24 _b	22 _b	23 _b
Chronic disease prevalence rates (%)					
Diabetes	9 _a	3 (M) _e 3 (F) _e 4 _a	11(M) _e 17(F) _e	2 _b	6 _b
Arthritis & Rheumatism	26 _a	16 _a	18(M) _e 25 (F) _e	9 _b	20 _b
Heart problems	7 _b	4 (M) _e 4 (F) _e	13(M) _e 11(F) _e	5 _b	7 _b
Hypertension	15 _a	8 (M) _e 11(F) _e 13 _a	22 (M) _e 26 (F) _e	8 _b	13 _b
Infectious Disease (rate per 100,000/yr)					
Tuberculosis	21 _c	1.3 _c	30 _c	92 _c	5.6 _c
Chlamydia	n/a	82 _d 194 _d	532 _d 1366 _d	1410 _f 2918 _f	n/a
Health Behaviours (% of pop)					
Smoking	42 _a	22 _a	38 _b	61 _b	37 _b

Table adapted from Canadian Institutes for Health Information. (2004). *Improving the health of Canadians: Aboriginal Peoples' health*. Retrieved from http://secure.cihi.ca/cihiweb/products/IHC2004_ch4_e.pdf²

²Data Sources for Table 1.

Data sources for Aboriginal (all and non-reserve):

a Tjepkema M. (2002). The health of the off-reserve Aboriginal population. *Health Reports—Supplement*13, 1–16. Catalogue no. 82-003-XIE. Data for the Aboriginal and non-Aboriginal population

population. One exception exists: the rates of chlamydia are substantially higher in Inuit populations and more than double the rate in First Nations people.

However, there is evidence that this trend is shifting and Inuit peoples' health has recently become a topic of concern. Similar trends of declining health status, increases in chronic disease, and higher mortality rates overall are being seen in the Inuit of the Canadian Arctic, a people previously reputed for having better overall health than their southern counterparts (National Aboriginal Health Organization [NAHO], 2002). A study of Alaskan Native women

are from the 2000/2001 Canadian Community Health Survey. These data are age-standardized to the Canadian population as used by the 2000/2001 Canadian Community Health Survey.

b Statistics Canada. (2003). *Aboriginal Peoples Survey 2001: Initial Release—Supporting Tables*. Ottawa: Minister of Industry. Catalogue no. 89-595-XIE. Not age-standardized. Custom tabulations for Overweight, Obesity, and Smoking figures.

c Health Canada. (2003). Reported new active and relapsed tuberculosis cases and incidence rate per 100,000 by birthplace—Canada and provinces/territories—2000. *Tuberculosis in Canada—2000*. Ottawa: Minister of Public Works and Government Services. <www.hc-sc.gc.ca/pphb-dgspsp/publicat/tbcan00/pdf/tbcan_2000_e.pdf>.

Data sources for Canada and Non-Aboriginal from references a, d, e and the following:

* Note that source *a* compares the Aboriginal and non-Aboriginal population within the Canadian Community Health Survey; sources *d* and *e* are for the Canadian population as a whole.

Data sources for First Nations:

d Health Canada. (2003). *A Statistical Profile on the Health of First Nations in Canada*. Ottawa: Health Canada. Data for First Nations on-reserve are collected by First Nations and Inuit Health Branch regional offices and provincial health departments. First Nations population figures are from the Indian Registry, estimating the on-reserve population as of December 1999 for all provinces except for British Columbia and Alberta where the on-reserve and off-reserve populations are included. These data are not age-standardized. Canadian rates for Chlamydia are from Health Canada data.

e Young T. K., O'Neil J., Elias B., Leader A., Reading J., McDonald G. (1997). "Chronic disease." In First Nations and Inuit Regional Health Survey National Steering Committee (Eds.) *First Nations and Inuit Regional Health Survey—National Report 1999*. St. Régis, QC: First Nations and Inuit Regional Health Survey National Steering Committee. Data are from the First Nations and Inuit Regional Health Survey. Diabetes, arthritis and rheumatism, heart problems, cancer and hypertension are age-sex-specific and age-adjusted to the Canadian population as used by the 1994 National Population Health Survey. Rates for all Canadians are from the 1994 National Population Health Survey. All data points obtained in custom tabulation from author.

Data sources for Inuit are from references b and from data for Nunavut (85% of population is Inuit):

f Health Canada (2002). Reported Genital Chlamydia Cases and Rates in Canada by Province and Sex, 1991–2000. Data source: Sexual Health and Sexually Transmitted Infections, Centre for Infectious Disease Prevention and Control. 2001 rates accessed through the Canadian Institute for Health Information website: <secure.cihi.ca/cihiweb/en/pirc_indicators_13d_ProvSex_e>.

Data sources for Métis from reference b and c.

demonstrated that the previously low incidence of heart disease in the far North has changed quite dramatically in a short time, and increases in chronic illness and poorer health status overall are on the rise (Witmer, Hensel, Holck, Ammerman, & Will, 2004).

Presently, Aboriginal peoples have markedly lower SES than most Canadians (see Table 2) and experience poverty and lower levels of education. Aboriginal identity is one of the most important factors associated with health disparities in Canada. As such, Aboriginal status has recently become a social determinant of health (Raphael, 2009) (Canadian Institute for Health Information [CIHI], 2004; Newbold, 1998; & Smith, 1999).

There are many historical and socio-cultural factors that impact the status of Aboriginal peoples' health today, including a history of colonialism, poor housing, residual trauma from residential schools, ongoing racism, government policies, life on reserve, and lack of power, self-determination and control (Canadian Institute for Health Information [CIHI], 2004; Newbold, 1998; & Smith, 1999).

Current health statistics. Aboriginal peoples in Canada continue to bear a disproportionate burden of both chronic and infectious diseases. Specifically, rates of diabetes, heart disease, tuberculosis, HIV/AIDS, and infectious disease are much higher in Aboriginal peoples than in the overall Canadian population (Health Canada, 2006; Reading, 2009; First Nations Centre, 2006). Despite the previously accepted notion that Aboriginal people had some type of natural immunity against CVD as past prevalence rates were extremely low, it is now clearly recognized that Aboriginal people have higher rates of CVD as compared to non-Aboriginal Canadians (Howard et al., 1999; HSFC, n.d.; Reading, 2009). In Canada, the leading cause of death in Aboriginal peoples over the age of 44, and for women, is from circulatory diseases, which accounts for 23% of all deaths (Health Canada, 2006). According to the First

Urban Aboriginal Peoples and Hypertension

Table 2

Education, Work Status, and Income (% of population)

	Aboriginal Peoples	Non-Aboriginal Canadians	First Nations	Métis	Inuit
No degree, certificate, diploma	52	33	55	66	46
High school	18	23	17	11	20
Trade school/ College	25	29	24	21	28
Bachelor's degree	4.4	16	4.1	1.9	5.3
Unemployment rate	19	7	22	22	14
Worked full time, full year	26	37	23	23	31
Low income in 2000	34	16	40	24	28

Table from Canadian Institutes for Health Information. (2004). *Improving the health of Canadians: Aboriginal Peoples' health*. Retrieved November 22, 2007 from http://secure.cihi.ca/cihiweb/products/IHC2004_ch4_e.pdf

Urban Aboriginal Peoples and Hypertension

Nations and Inuit Regional Health Survey, Aboriginal people have three times the rate of heart disease and, although rates vary geographically, two to three times the rate of diabetes (First Nations Centre, 2006; Reading, 2009).

Further, consultations with Aboriginal peoples in central Saskatchewan highlighted that CVD as well as diabetes and its related diseases were two of the top five health concerns identified (Indigenous Peoples Health Research Centre [IPHRC], 2006). Almost 40% of Aboriginal people in Canada with diabetes also have hypertension (PHAC, 1999). Since rates of diabetes are epidemic in Canadian Aboriginal peoples, these health statistics merit attention (Reading, 2009; Young, Reading, Elias, & O'Neil, 2000).

Further, obesity rates are at 55% compared to the Canadian rate of 48% (HSFC, 2003). The incidence of smoking in 1997 in First Nations populations was 62% in sharp contrast to the Canadian average of 24% (Health Canada, 2006). These data have significant consequences as both obesity and smoking are risk factors for the development of hypertension.

Local population. The province of Saskatchewan has one of the highest proportions of Aboriginal people in Canada (14% versus the national average of 4%), and there are high proportions in all urban centres, including Saskatoon (9.3%). Other than Winnipeg (10%), the local population represents the highest proportion of urban Aboriginal peoples in Canada. Just over half of Saskatoon's Aboriginal population (21,535 people) identifies as First Nations whereas around 40% identify themselves as Métis and less than 1% identify as Inuit (A. B. Anderson, 2005; Statistics Canada, 2006).

The local Aboriginal population is rapidly increasing and the number of First Nations people in Saskatchewan, in particular, is expected to double in the next decade (A. B. Anderson,

2005). Already, between the years of 1996-2001, the city of Saskatoon grew by 3.1% while the Aboriginal population increased by 7.3% (A. B. Anderson, 2005).

The growth observed among Aboriginal peoples has occurred for a couple of reasons. First, Registered Indians in Saskatchewan have a much higher fertility rate than the rest of the provincial population, and this rate is higher than in any other Canadian province (A. B. Anderson, 2005). Further, in Saskatoon, half of the Aboriginal population is under 20 years of age and it is this population of younger adults with the highest birth rates (Statistics Canada, 2006). Contrary to the increasing number of Aboriginal people in both Saskatoon and Saskatchewan, many non-Aboriginal people emigrated to other provinces in search of economic pursuit.

Not only is the local Aboriginal population increasing, but among the majority of Aboriginal peoples (i.e., First Nations people) in Saskatoon, much diversity is observed. For instance, different languages spoken in Saskatoon include Cree/Nehiyawak, Ojibway/Saulteaux/Anishinabeg, Mechif, Sioux/Dakota, Athapaskan/Dene, Assiniboine/Nakota, Micmac, Inuktitut etc. (A. B. Anderson, 2005).

Trend toward urbanization. More than half the Aboriginal population in Canada currently resides in urban centres (Environics Institute, 2011; NAHO, 2008; Statistics Canada, 2006). Aboriginal people leave reserve communities for various reasons, including being near family, to pursue higher education, employment, or other opportunities, to have access to health services or affordable housing, and to escape boredom, family violence, or substance abuse on reserve (A. B. Anderson, 2005). Such trends toward urbanization have implications for the decline of Aboriginal populations on reserves and in rural areas (Environics Institute, 2011; NAHO, 2008). In the last two decades, the population of First Nations people in Saskatchewan

has doubled, and approximately half of those individuals live off-reserve, mostly in urban areas (Hunter, Logan, Goulet, & Barton, 2006; Vital Statistics of Saskatchewan, 2001).

The Aboriginal Peoples' Survey (APS), a nationwide health survey, was conducted to understand the well-being of urban Aboriginal peoples (Statistics Canada, 2001). The APS showed that, among non-reserve populations of Aboriginal people, 56% reported that they were in excellent or very good health, 26% indicated that their health was good, whereas 17% described their health as fair or poor. When broken down by age, however, health ratings begin to decline at a faster rate than in the non-Aboriginal Canadian population (Statistics Canada, 2001). For instance, between the ages of 55-64, 51% of the total Canadian population surveyed self-reported excellent health compared to 38% of Aboriginal people. This decline occurs at a more dramatic rate in Aboriginal women as the average life expectancy for Aboriginal women is 7 years less than for non-Aboriginal Canadian women (75 versus 82 years of age) (Stout, Kipling, & Stout, 2001). Similarly, the rate of contracting diabetes is nearly double in Aboriginal women than men (Health Canada, 2000). Reasons for the poorer overall and faster decline in Aboriginal women's health remain unclear. However, a recent report (K. Anderson, 2005) highlighted the legacy of colonialism on Aboriginal women's identity as a primary contributor to poor health.

Overall, it is imperative that we begin to investigate the beliefs of Saskatoon's Aboriginal residents with hypertension as they represent a significant proportion of the city and of the Aboriginal population in the province. A greater understanding of health beliefs amongst urban Aboriginal people may assist in the planning and delivery of health services for those afflicted by disease and poor health.

Hypertension and Aboriginal People

Recent data indicate that the incidence of hypertension is deemed to be higher in Aboriginal peoples than the overall Canadian population (e.g., 20% compared to 16.4%) (HSFC, 2006; First Nations Centre, 2006). Further, this ethnic discrepancy may be increasing as the prevalence of diabetes, a known risk factor for hypertension, among Aboriginal peoples became identified as an epidemic over a decade ago (First Nations Centre, 2006; Reading, 2009; Young, Reading, Elias, & O'Neil, 2000). Both in Saskatoon and in Saskatchewan, the population-based incidence of hypertension in 2001 was 14% (Statistics Canada, 2001).

Figure 1 displays the prevalence of hypertension by age comparing the rate among First Nations people to the Canadian prevalence rate. Not only are the rates consistently higher for First Nations people, but also for women (First Nations Centre, 1999). However, since the elevated rates for women are predominantly seen in the post-menopausal population, when averaged together, women have lower overall rates. Consequently, this figure identifies that First Nations people have 2.5 (women) and 2.8 (men) times higher rates of hypertension than the non-Aboriginal Canadian population (First Nations Centre, 1999; Reading, 2009).

Further investigation is warranted to clarify the prevalence of hypertension adjusted by Nation or Aboriginal group by province, territory and region. Such clarification is essential in order to grasp the reality of the distribution and impact of hypertension among Canada's Aboriginal peoples, including regional, cultural, and community variability.

Social Determinants of Health

It is now well understood that living conditions bear a stronger influence on individual health than medicine or individual behaviours (Mikkonen & Raphael, 2010; PHAC, 2003A). Such influential conditions are referred to as the social determinants of health [SDOH] and are the factors that explain the disparities in our population's health. These determinants interact to

inform a more holistic understanding of health and well-being. They further the understanding that the sequelae of inequalities in living conditions are health inequalities.

Canada has been at the forefront of the development of the SDOH literature with the Public Health Agency of Canada working alongside the World Health Organization. As such, Canada has been referred to as the “health promotion powerhouse” (Mikkonen & Raphael, 2010, p.7). A leader in SDOH theory, Dennis Raphael (2007, 2009) has written extensively about the SDOH that most affect Canadians. In recent years, Raphael (2009) expanded the original 11 SDOH from the PHAC to 14 SDOH that most apply to Canadians. In alphabetical order, the updated SDOH include:

1. Aboriginal status
2. Disability
3. Early life
4. Education
5. Employment and working conditions
6. Food insecurity
7. Gender
8. Health services
9. Housing
10. Income and income distribution
11. Race
12. Social exclusion
13. Social safety net
14. Unemployment and job security

Urban Aboriginal Peoples and Hypertension

Figure 1. Age-Sex-Specific and Age-Adjusted Prevalence of Self-Reported Hypertension %

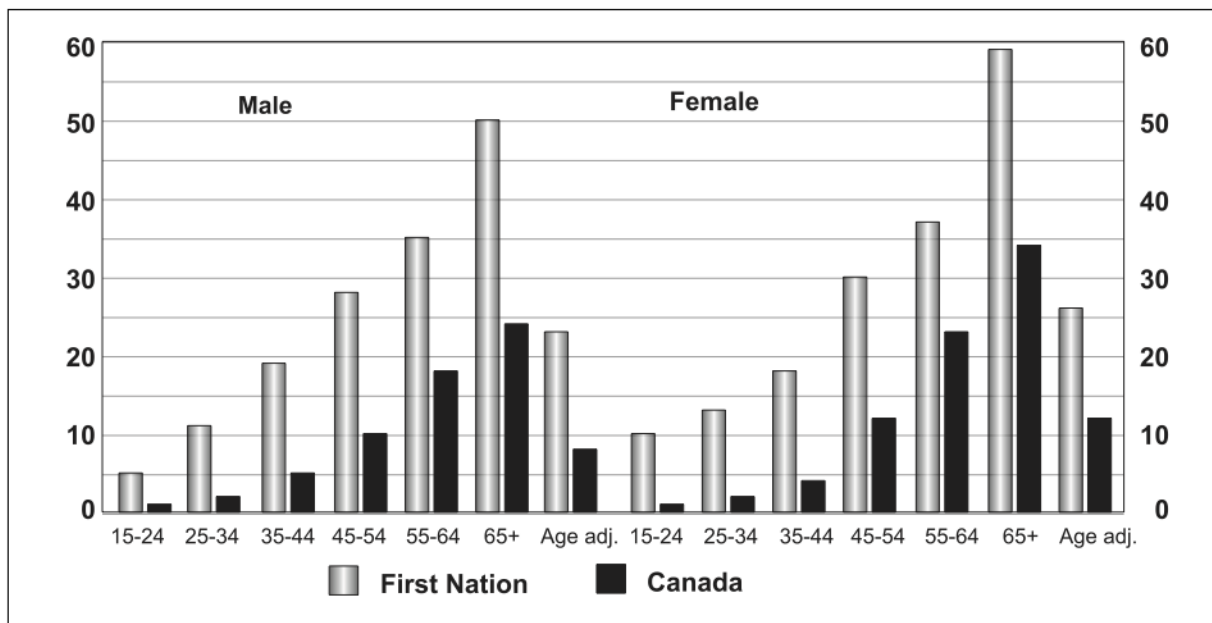


Figure from First Nations Centre (1999) First Nations and Inuit regional health survey. First Nations and Inuit regional health survey National steering committee. Retrieved from http://www.rhs-ers.ca/sites/default/files/ENpdf/RHS_1997/rhs_1997_final_report.pdf

I will examine several SDOH in greater detail, with particular relevance to the local setting, the city of Saskatoon.

Income and income distribution. Of all the identified social determinants, income, and its distribution, has the strongest relation to health disparity (Marmot, 2005; Mikkonen & Raphael, 2010; Reading, 2009; WHO, 2008). According to Anderson, A.B. (2005), both Saskatoon and Regina have the largest rates of Aboriginal people living in poverty compared to other western, Canadian cities. This is defined by a statistical measure of low-income cut-off which Statistics Canada, 2009 defines as “an income threshold below which a family will likely devote a larger share of its income on the necessities of food, shelter and clothing than the average family” (Statistics Canada, 2009). In Saskatoon, economic disparities are resulting in higher disease rates. Low-income residents of Saskatoon, compared to their higher income counterparts, are:

- “1458% more likely to attempt suicide
- 1389% more likely to have chlamydia
- 3360% more likely to have hepatitis C
- 676% more likely to have gonorrhea
- 1549% more likely to have a teenager give birth to a child
- 448% more likely to have an infant die in the first year
- 52% more likely to have low self report health
- 165% more likely to have diabetes
- 277% more likely to have heart disease
- 95% more likely to have high blood pressure” (Lemstra & Neudorf, 2008b, p. 5).

A local study conducted by the Saskatoon Health Region found that residing in lower-income neighbourhoods is more strongly associated with poor health status and greater health care utilization (Lemstra, Neudorf, & Opondo, 2006). “Low-income neighbourhoods” are those in which more than 30% of households meet the criteria for low-income cut-off (Lemstra et al., 2006).

Although residing in particular neighbourhoods may reduce well-being, the issues are complex and do not reflect a straightforward cause and effect relationship or automatically predict poor health (A. B. Anderson, 2005). Of note, increased health care utilization in such neighbourhoods was more strongly related to higher disease rates and need for services as opposed to irregular utilization patterns (Lemstra et al., 2006; Lemstra & Neudorf, 2008a). Such diseases consisted of higher rates of mental disorder, suicide attempts, diabetes, coronary heart disease, all of which impact a higher rate of overall mortality (Lemstra et al., 2006).

Unemployment and job security. In 2001, the rate of unemployment for Aboriginal people in Saskatoon was 23% compared with 5% of the non-Aboriginal population (A. B. Anderson, 2005). In 2012, the overall rate of unemployment in Saskatchewan was 5.1% (Statistics Canada, 2012). The national rate of unemployment was double for First Nations people living on reserve than off-reserve (Mikkonen & Raphael, 2010).

Education. About one third to one half of all Aboriginal adults living in Saskatoon has not attained a high school education (A. B. Anderson, 2005). Nonetheless, urban Aboriginal people in Saskatoon and Regina are becoming more educated than in the past and the rate of those who have attended University (i.e., approximately 25%) has set a standard for the rest of the country (A. B. Anderson, 2005). Approximately 10% of students at the University of Saskatchewan self-identify as Aboriginal (A. B. Anderson, 2005). As noted by Anderson,

educational status is related to occupational achievement which, in turn, affects SES and one's ability to afford proper housing.

Housing. A recent housing crisis has emerged in Saskatoon, which is typified by low vacancy rates and mortgage inflation. The rate of homelessness and affordable housing in lower-income neighbourhoods of Saskatoon is striking. Aboriginal residents of Saskatoon still predominantly rent rather than own housing. In 2001, 17.2% of Aboriginal households were renting and nearly half of Aboriginal residences were found to be in "core housing need" (A. B. Anderson, 2005, p.52). Core housing is defined as:

"households which are unable to afford shelter that meets adequacy, suitability, and affordability norms...Affordability, one of the elements used to determine core housing need, is recognized as a maximum of 30 per cent of the household income spent on shelter" (Canadian Mortgage and Housing Association, section 4, para. 1).

Despite the apparent housing crisis, housing conditions for Aboriginal peoples in Saskatoon are improving in some respects. For instance, more Aboriginal people are becoming home-owners and people are residing under less crowded conditions (A. B. Anderson, 2005). Similarly, there is more dispersion occurring throughout the city and Aboriginal people are moving to more middle-class neighbourhoods (A. B. Anderson, 2005). Of those individuals residing in low-income neighbourhoods, crime was identified as a major concern (A. B. Anderson, 2005; Environics Institute, 2011). Nonetheless, A. B. Anderson's (2005) report revealed that the respondents preferred to stay living in such neighbourhoods.

Aboriginal status. Raphael (2009) highlighted the addition of Aboriginal status to the list of SDOH. In his seminal work, he indicated that the relation between Aboriginal status and health outcomes warrants specific attention (Raphael, 2009). Despite the fact that culture was

previously identified as a SDOH, Aboriginal status alone merits deliberate consideration as it is specifically related to factors such as a history of colonialism that other minority groups have not experienced (Mikkonen & Raphael, 2010).

Aboriginal Determinants of Health

Although Aboriginal status is now a named SDOH in Canada, it is pivotal that such naming does not promote the notion that health cannot be modifiable for Aboriginal people. Likewise, there is risk of faulting Aboriginal people for their poor health, simply because they are Aboriginal (Lemstra & Neudorf, 2008a). Aboriginal health status remains highly correlated with low income, poor educational achievement and high unemployment rates (A. B. Anderson, 2005; Lemstra & Neudorf, 2008a; Mikkonen & Raphael, 2010). Groundbreaking research by Lemstra & Neudorf (2008a) revealed that in Saskatchewan, when these other determinants are adjusted for, Aboriginal status alone is no longer significantly related to health outcomes. However, examples of other communities that have high overall income levels (e.g., the Hobbema reserve in Alberta) still display exceedingly high rates of social dysfunction (Blatchford, 2001). Therefore, Aboriginal status is highly correlated with various social determinants of health, and further carries its own related factors that situate it within a broader context. As such, the National Aboriginal Health Organization (NAHO) created the Aboriginal determinants of health which clarify additional factors related specifically to the disproportionate burden of illness among Aboriginal peoples (NAHO, 2006).

NAHO's (2006) Aboriginal determinants of health [ADOH] consist of:

1. Colonization
2. Globalization
3. Migration

4. Cultural continuity
5. Territory
6. Access
7. Poverty
8. Self-Determination

Colonization. The impact of colonization and residual trauma from residential schools persists today. In Saskatoon, over 80% of Aboriginal people have personally, or have a first degree relative who, experienced residential schools (Environics Institute, 2011). Also, the Aboriginal Women’s Health Research project found that due to the “legacy of colonization,” Aboriginal women experience “lower life expectancy...., higher rates of suicide, substance abuse, spousal violence, incarceration, sexually transmitted diseases, disability and chronic illness” (A. B. Anderson, 2005, p. 8; Stout et al., 2001). Accordingly, the influence of colonialism persists today in Aboriginal communities and greatly impacts the health status of Aboriginal peoples.

Globalization. This broad determinant consists of economic changes such as privatization, decentralization, and health reform (NAHO, 2006). In addition, environmental factors such as climate change also impact health status. For some Aboriginal communities, environmental degradation has resulted in a loss of valuable local food sources and has created a dependence on high caloric, refined foods that advance obesity and other long-term health consequences (CIHI, 2004; Kuhnlein & Receveur, 1996; Reading, 2009).

Migration. Aboriginal peoples are generally more community- and family-oriented than their Western counterparts (King, Smith, & Gracey, 2009; Poonwasie & Charter, 2001; Royal Commission on Aboriginal Peoples [RCAP], 1996; Reading, 2009). Further, social support,

whether it is from friends, family, neighbours, colleagues, or the community, remains an important value for many Aboriginal peoples. The concept of family is broader and non-blood related others are referred to with family titles such as ‘aunty, brother’ and so forth (RCAP, 1996). As Aboriginal culture emphasizes interconnectedness and interrelatedness, social support may provide a buffer against poor health (Arnold and Bruce, 2005). Nonetheless, transitions are occurring in Aboriginal communities and in close relationships as many people migrate off-reserve to nearby cities and towns.

Social isolation and the dissolution of strong community ties are reported in those who migrate off-reserve or lose touch with their traditional culture (Newbold, 1998). Colonialism in itself bears a strong relation to the dissolution of social support embedded within the family unit in traditional Aboriginal societies (IPHRC, 2006). Once away, there may be a sense of isolation as the family and community support is no longer apparent or easily accessible. Migration is also associated with poor lifestyle changes including increased obesity, poor nutritional choices, and decreased physical activity (NAHO, 2006).

In addition, urban services may be foreign, difficult to navigate and at times even result in racist encounters (Arnold & Bruce, 2005). Some people easily cope and make the transition whereas others feel lost or isolated, and subsequently become under-served, particularly with regard to health and social services (RCAP, 1996). For many reasons, including remaining close to relatives or community members, ethnic segregation in cities, and decreased cost of living, Aboriginal people often end up in low income neighbourhoods in Canada (A. B. Anderson, 2005). As living in poverty and social isolation are related to poorer health outcomes, it is essential that hypertension is understood holistically.

Cultural continuity. When Aboriginal people are urbanized and disconnected from their reserve community, they may become further disconnected from traditional teachings and practices (NAHO, 2006). Even without the trend toward urbanization, many Aboriginal people have moved away from indigenous knowledge and moved toward assimilation in the dominant culture (NAHO, 2006). Such loss of traditional understandings of health isolates Aboriginal individuals and leads to health disparity.

Territory. Similar to the environmental devastation discussed previously, loss of physical territory or healthy territory has detrimental impacts on Aboriginal peoples' health. There are, unfortunately, too many reports of reserve land being spoiled by industries where inhabitants lose access to clean drinking water. The state of the natural environment is a vital component in an Aboriginal worldview of health and must be considered as a factor influencing individual health (NAHO, 2006).

Access. Issues of access vary depending on geographic location. Many reserve communities are rurally-based and/or remote where the provision of health services and community resources is limited (NAHO, 2006). Under such circumstances, people have to travel to larger municipal centres to receive care and the majority of specialists are located only in large centres such as Regina and Saskatoon. Yet, even within urban Aboriginal communities, particularly in low-income neighbourhoods, barriers to accessing services still exist (NAHO, 2006). For instance, low-income neighbourhoods in central Saskatoon constitute a "food desert" where barriers to accessing healthy food, e.g., the need for transportation, distance to food store, and cost of food (Woods, 2003).

Poverty. In Canada, Aboriginal people's income is substantially reduced compared to non-Aboriginal Canadians (Mikkonen & Raphael, 2010). Approximately one quarter of non-

reserve based Aboriginal people in Canada fall below the low income cut-off (previously defined); this rate is double the Canadian average (Mikkonen & Raphael, 2010). Low-income strongly correlates with poor educational attainment and barriers to employment all of which relate to Aboriginal status (Lemstra & Neudorf, 2008a). Such rampant poverty in Aboriginal communities is referred to as “fourth world,” whereby individuals experience “third world” conditions in developed nations (NAHO, 2006). Fourth world status is generally found only in Indigenous groups worldwide. Therefore, in Canada, Aboriginal identity and economic disparity remain highly correlated (NAHO, 2006; RCAP, 1996).

Conditions in Saskatoon’s inner cities are reflective of fourth world status as a high correlation exists between poverty and Aboriginal status (Lemstra & Neudorf, 2008a). In six Saskatoon neighbourhoods identified as low-income, nearly half the population was Aboriginal (A. B. Anderson, 2005; Lemstra et al., 2006). Further, in 2001, 52% of Aboriginal people in Saskatoon lived below the poverty line (A. B. Anderson, 2005). Although a recent report suggested that an Aboriginal middle class is emerging in Saskatoon, and that Aboriginal people are dispersing around the city, these findings may be somewhat misleading; even though families are moving to middle-class neighbourhoods, they still predominantly reside in apartment blocks as opposed to houses (A. B. Anderson, 2005). Overall, the majority of Aboriginal residents of Saskatoon are considered to have low income.

Since individuals most affected by illness tend to be those disproportionately impacted by poverty and members of ethnic minority groups, such individuals are also less likely to be privileged enough to afford the luxury of engaging in lifestyle modifications, such as joining a gym or affording healthy food (Townsend, 2009). Good health is expensive to maintain. Access to high quality and nutritious food remains highly correlated with income (Kirkpatrick &

Tarasuk, 2003). Despite all efforts to encourage individuals with chronic illness to eat better, they are typically the ones who simply cannot afford to do so (Kirkpatrick & Tarasuk, 2003).

Self-determination. Despite such negative factors influencing Aboriginal peoples' health, there has been a recent shift in communities toward fostering self-determination and even sovereignty. Attempts to revitalize cultures and gain more control through self-governing, for example, are notable factors in the promotion of health that are occurring today among Aboriginal communities (CIHI, 2004; Reading, 2009). Such attempts appear to be successful, as half of the Aboriginal respondents to the Urban Aboriginal Peoples Study (EnviroNics Institute, 2010) perceived Aboriginal cultures in Saskatoon as becoming stronger.

Since Aboriginal health is strongly influenced by broader factors such as geographical location and access to services, there are no overall summary generalizations that can be made about the current state of Aboriginal health. Aboriginal health varies considerably. Within- and between-group variability must be considered for First Nations, Métis, and Inuit peoples. Therefore, it is essential that we maintain a clear sense of history, current health trends, and variability in these trends, and recognize strengths when generating a current portrayal of Aboriginal peoples' health.

Broader Understandings of Health

Upon examination of the national guidelines and best practices for hypertension treatment (CHEP, 2012; HSFC, 2011a), it is apparent that the majority of the documents focus on a biomedical understanding of individual health and of modifying individual health behaviours. Nevertheless, through an exploration of the SDOH and the ADOH, it is apparent that income among other key factors significantly relates to the onset and maintenance of hypertension in all Canadians, Aboriginal and non-Aboriginal.

The economic burden of poor health and disease in 2010 in Canada was estimated to be 191.6 billion dollars (CIHI, 2010). Not only is disease an economic burden on health care resources, but in the long-term, poor health impacts our citizens' ability to contribute productively to the workforce and the national and global economy (Townsend, 2009). Further, health care institutions, under great financial pressure, are being required to tighten and restrict their budgets. As a result, greater responsibility gets placed on the individual to maintain his or her health. Public education regarding health promotion remains focused on modifying lifestyle and health behaviours aimed at reducing overall treatment costs. Such strategies miss the real prevention needs: modifying deeply rooted factors such as poverty and lack of access.

A vicious cycle occurs whereby economic factors strongly influence health, yet our interventions continue to focus on individual behaviour. Our focus on biomedical risk factors is lacking an understanding of the holism of health. I explore the consequences of such a narrow perspective of health in chapter 3.

Knowledge Translation and Policy

Overall, the translation of existing Canadian health policy into action continues to lag, as our current interventions do not adequately reflect the strong relations among health, socioeconomic disparity, and the structure of our institutions (Kirkpatrick & Tarasuk, 2003; Manitoba Centre for Health Policy, 2010; Townsend, 2009). Instead, the focus remains on individual treatment efforts which are also referred to in public health as downstream (or tertiary) interventions (McKinlay, 1998). Downstream interventions consist of treatment for those individuals already affected by disease, including lifestyle modification through behaviour change and education. According to McKinlay, only approximately 5% of the population afflicted by the targeted disease benefits from downstream intervention despite the prominence

of such efforts. However, other potential levels of intervention include midstream (secondary) and upstream (primary). Midstream interventions consist of prevention efforts including public education and/or programming about healthy eating and the merits of physical activity. Such midstream intervention efforts are aimed at those affected by a targeted disease, and at preventing others from developing the disease. Upstream interventions comprise initiatives within macro-level structures - such as government and institutions- and target change at the population-level. McKinlay (1998) provided examples of upstream intervention, including reduced taxation for healthy people, creating bike lanes or public transit, and healthy workplace incentives such as insurance coverage for fitness facilities. McKinlay (1998) posited that both midstream and upstream interventions have a greater impact than downstream interventions. This finding aligns with the classic Rose Theorem which demonstrates that small changes at the population level create a greater impact than large changes in a few individuals (McKinlay, 1998; Rose, 1992).

Nevertheless, progress is occurring with the implementation of more midstream and upstream interventions as existing health policy in Canada is being transferred into action (L. Hansen, personal communication, May, 2009; PHAC, 2003b). For instance, soft drink vending machines are being removed from schools. Additionally, as a result of clear evidence indicating that the vast majority of Canadians over-consume sodium and that this over-consumption is most related to pre-packaged and processed foods, recommendations were put forth to the Canadian government and policies set in place to address this issue at the population level (Penz, Joffres, & Campbell, 2008). In 2007, the Blood Pressure Canada health policy was created, which targeted a population-based reduction of sodium. This policy was supported by a multitude of health care organizations. As a result of this initiative, Campbell's (in Canada only) created a reduced-

sodium product line (Penz et al., 2008). More population-based changes, spearheaded by the Government of Canada, to restrict the amount of sodium in our food are pending (Penz et al., 2008). Generally, such population-based dietary modifications are proving effective at reducing sodium consumption among Canadians (Mohan, Campbell, & Willis, 2009).

Similarly, Canada was the first country to implement graphic, disturbing images of the health consequences of smoking on cigarette packaging in an effort to reduce smoking rates (Hammond et al., 2007; Hammond, Fong, McDonald, Cameron, & Brown, 2003). Specifically, the effect of such images on smoking cessation has been well documented (Hammond, Fong, McDonald, Brown, & Cameron 2006). Such initiatives reflect the effectiveness of midstream and upstream interventions.

The broadening of health policy to address macro-level factors is also transpiring internationally. The World Health Organization (WHO) made three recommendations in August 2008 when the Final Commission to the Social Determinants of Health report was released (WHO, 2008)³. These recommendations are:

- “1. Improve daily living conditions
2. Tackle the inequitable distribution of power, money, and resources
3. Measure and understand the problem and assess the impact of action”

(WHO, 2008, p.1).

The recommendations include goals and specific strategies for putting each recommendation into action. Specific strategies for improving daily living conditions include ensuring all children receive an education, increasing affordable housing, investing in rural areas,

³ For a more detailed description of the Final Commission to the Social Determinants of Health, see http://www.who.int/social_determinants/thecommission/finalreport/closethegap_how/en/index1.html

access to water and proper sanitation, fair employment and working conditions, ensuring social protection policies, and providing universal health care. Such strategies are aligned with addressing health disparity by focusing on the social determinants of health.

The notion of upstream health interventions targeting power, money, and inequitable resources might seem impractical and overzealous, as it is a completely radical shift from traditional downstream health promotion which targets individual behaviour (McKinlay, 1998). However, the WHO put forth strategic goals to promote upstream interventions, such as altering existing governmental structures to prioritize equality in health care, progressive taxation, gender equity, and fair representation of disadvantaged groups to major decision-making.

The final recommendation involves evaluating both new and existing interventions and databases to monitor whether programs are achieving their goals. The commission calls on the WHO, governments at all levels, the public sector including agencies, academic and research institutions, and private industry to be responsible for creating change and orienting toward the recommendation, including investing in research, disseminating research results, and evaluation and training.

Therefore, great strides are occurring with the advancement of academic knowledge, government and industry involvement, demonstrating that partnerships and collaboration are feasible and ultimately that changes are possible at the societal level as influenced by public policy (Penz et al., 2008). Finally, the formation of policy ought to expand to be more inclusive of Aboriginal peoples through engagement with individuals and communities.

Part Two: Adherence and Treatment Issues

Adherence to treatment recommendations is an important aspect of any disease state or condition. Adherence, for the purpose of this study, is defined as the extent to which a patient's

behaviour is consistent with medical or health and treatment advice from a professional (Meichenbaum & Turk, 1987).

Factors implicated in poor adherence to medications or treatment recommendations for any health condition include longer or ongoing treatments, poor communication with physicians about illness and medication, the perceived and actual side-effects from drugs, having an external locus of control, being male or of younger age, and lower levels of education (Balfour et al., 2006; Hong, Oddone, Dudley, & Bosworth, 2006; Richardson, Simons-Morton, & Annegers, 1993). Likewise, chronic conditions, such as hypertension, tend to result in poorer adherence rates (Balfour et al., 2006). However there is hope; patients who are more actively involved in their own treatment, experience greater self-efficacy and are more likely to adhere.

One of the strongest predictors of non-adherence to treatment recommendations, across medical conditions, is depression (Balfour et al., 2006). It is hypothesized that the common depressive symptoms of lethargy, apathy, and anhedonia can result in reduced adherence to medical and health regimes, such as eating a low-sodium diet and exercising, thereby creating multiple risk factors for hypertension (Bosworth, Bartash, Olsen, & Steffens, 2003).

Theories of adherence. Well established adherence theories exist, none of which have been validated with Canadian Aboriginal peoples. While it is inappropriate to generalize from a non-Aboriginal sample to an Aboriginal sample, it is important to be cognizant of dominant theoretical positions.

The Health Belief Model (HBM) is the original theory applied to adherence behaviour in health psychology and it has been implemented in many contexts (Cook, 2007). The HBM helps to illustrate why people choose particular health behaviours. This theory is based on the notion that behaviour is motivated by the amount of perceived threat of illness combined with a belief

that a certain action (health behaviour) will effectively reduce that threat (Rosenstock, 1974). Four assumptions are inherent in this model: (1) the individual needs to believe that s/he is susceptible to a particular disease; (2) that with this disease there is a serious threat to one's health; (3) that action taken to reduce one's likelihood of contracting the disease will be beneficial; and (4) that disease intervention will be relatively easy and free of significant "barriers" (Cook, 2007; Rosenstock, 1974). For instance, if an individual with hypertension believed that the disease, left untreated, would harm his/her health and that, with medication, the threat would be subsequently reduced, it would be likely that individual would adhere to antihypertensive medications.

The Theory of Reasoned Action (TRA) posits that attitudes (comprised of personal beliefs regarding behavioural outcomes and the evaluation of these outcomes) and subjective norms (beliefs regarding what salient others want you to do in regard to the behavioural outcomes and your motivations to comply with these salient others) combine to form intentions which then predict behaviours (Ajzen & Fishbein, 1980). So, for example, if the behavioural target is taking antihypertensive medication, then attitudes would be formed via the following: an individual might believe that the medication will cause him/her to gain weight, and s/he evaluates this outcome as likely and bad; but s/he might also believe that the medication will reduce blood pressure and evaluate this outcome as likely and beneficial. Hence, various beliefs and their evaluations will be combined to form an overall positive or negative attitude toward the outcomes of taking hypertension medications.

Simultaneously, subjective norms would be formed via considering the following: a woman's mother encourages her to take medication, but she is disinterested in what her mother wants. In contrast, her husband is against her taking medication and she is determined to do what

he wants. These various considerations are added together to form an overall subjective norm. Together the overall subjective norm and the overall attitude combine to form an intention regarding the behaviour in question.

A more encompassing theory is the Theory of Planned Behaviour (TPB) (Ajzen & Madden, 1986) which places emphasis on behavioural intention that consists of attitudes, norms, and perceived control over a situation. These three factors combine to form a behavioural intention which determines health behaviours. This theory, therefore, builds from the TRA by incorporating non-volitional and more complex behaviours (Cook, 2007). For instance, if an individual holds a belief that “eating better will reduce my blood pressure” and his/her attitude is “my family believes I should diet” and the perceived control is “I can change my diet”, then likely this individual’s intention will be to diet with subsequent behaviour to follow. A full appraisal of the perceived amount of control encompasses assessing the degree of opportunity, barriers, and one’s own ability. Such factors ultimately determine whether individuals engage in health behaviours.

Social Cognitive Theory is an expansion of the HBM with the addition of self-efficacy, or an individual’s appraisal of his/her capacity to execute a task successfully (Bandura, 1986). It is understood that self-efficacy is the missing ingredient from the HBM. This theory distinguishes between efficacy expectations (i.e., believing one has the capacity to execute behaviour change) and outcome expectations (i.e., knowing what the likely outcome would be if a particular behaviour occurred) (Cook, 2007). For instance, an individual may strongly believe that quitting smoking will benefit his/her health but may not believe that s/he has the capacity to quit in the moment. If an individual believes that s/he has the control or ability to reduce his/her own blood pressure, and thinks that reducing blood pressure leads to improved health status, s/he

will likely take steps to do so, as opposed to feeling helpless. The notion of self-efficacy has been successfully adopted into the HBM, TPB, and the Trans-theoretical Model.

The Trans-theoretical Model (TTM) (Prochaska, DiClemente, & Norcross, 1992) is based on the theoretical stages of change and proposes health treatment goals and interventions designed for each stage. This model contends that an individual will change on his/her own accord and will also change with the help of others (Cook, 2007). Stages of change include: precontemplation, contemplation, preparation, action, and maintenance stages. Along with the stages of change, the TTM also emphasizes the process involved in change, self-efficacy, and a cost-benefit analysis to the intended change. This model is useful because it recognizes individuals' readiness to change at each stage and caters to an individualized approach.

Johnson (2002) developed the Medication-Adherence-Model (MAM), as a result of ongoing difficulties with patients' adherence to hypertensive medications. It was designed in response to the inability of other theoretical models to fully capture adherence behaviour specific to hypertension (Johnson, 2002).

This theoretical model postulates that there are three core concepts related to adherence and that non-adherence can be intentional or unintentional. The first concept is *purposeful action* where the individual cognitively chooses to follow treatment advice "based on perceived need, effectiveness, and safety" (Johnson, 2002, p. 184). For instance, the individual believes that treatment will be helpful in reducing blood pressure and therefore s/he strictly adheres to the treatment recommendations. The next concept is *patterned behaviour*, where the habit or ritual of following treatment recommendations is established. Interruptions in routine, timing, or location may cause unintentional non-adherence. The final concept is *feedback*, which is defined as "the degree to which information, facts, prompts, or events reinforce the need to maintain or

modify medication-taking” (Johnson, 2002, p. 187). This latter concept is mediated by a feedback process where the individual uses an appraisal system to determine adherence to treatment recommendations. The MAM posits that all three concepts interact to influence adherence to treatment recommendations. This model, however, is rarely used to inform studies with diverse populations. Until more is understood about beliefs and perceptions of the disease for Aboriginal peoples, the applicability MAM for Aboriginal peoples is unknown.

Overall, the aforementioned theories inform individual health behaviour. Nevertheless, I have demonstrated that health is influenced by more complex, societal-based factors. As such, I aim to understand the impact and understanding of hypertension within a broader context, incorporating an understanding of the social and Aboriginal determinants of health (NAHO, 2006; Raphael, 2009).

Adherence and Hypertension

Poor adherence to treatment recommendations is a major factor in failing to control hypertension (Grant, Singer, & Meigs, 2005). Rates of medication non-adherence for hypertension are estimated to vary from 20% to 80% (Hong et al., 2006). Hypertension, left untreated, increases one’s risk for CVD by three or four times and stroke by seven times (Dawber, 1980). Therefore, poor adherence to treatment recommendations for hypertension has deleterious, and potentially fatal, consequences and results in overutilization of health resources and expenditures.

As previously described, best practices for hypertension treatment include antihypertensive medications and lifestyle modifications (e.g., increased physical activity, healthy diet, reduced sodium, etc.), the latter in particular for people with pre-hypertension. Low adherence rates with anti-hypertensive medications are well validated due to the asymptomatic

nature of the disease combined with the evident side-effects from the drugs (Hong et al., 2006). Many patients report that taking antihypertensive medications causes them to feel worse than if the disease were left untreated (Garro, 1988; Hong et al., 2006). Moreover, it is estimated that as many as two-thirds of those diagnosed with hypertension are not managing their disease well (Chobanian et al., 2003) and yet hypertension is one of the main concerns broached with physicians (Vasan et al., 2002).

A barrier to initiating medication (primary non-adherence) for hypertension is the belief that medication is ineffective (Mazor, Fischer, & Billings-Gagliardi, 2008). Decisions to begin a course of antihypertensive treatment have been found to be strongly related to the satisfaction of the communication with a physician, perceived trustworthiness of the physician and whether the patient believes that medication is helpful (Mazor et al., 2008; Roumie et al., 2011).

Empirical studies on adherence are a limited source of information as frequently those who do not adhere to treatment advice often drop-out of the studies and their data are discarded. Novel and more expansive understandings and ways of informing the medical community about beliefs surrounding treatment recommendations are needed.

A couple of qualitative studies have recently been conducted examining adherence to hypertension treatment, including research by Boutin-Foster, Ravenell, Greenfield, Medmim, & Ogedegbe (2009) which created a culturally-appropriate workbook “Living with Hypertension: Taking control” based on interview responses of African American respondents. A second study of interest was a meta-interpretation of 11 previous qualitative studies (Schlomann & Schmitke, 2007). The synthesis of studies revealed that expert versus lay beliefs about hypertension varied, and impacted the dynamics of health care encounters (Schlomann & Schmitke, 2007). However,

none of these qualitative studies are Canadian. Likewise, the Canadian literature on adherence to hypertension treatment recommendations is sparse and dated.

Ethnic and cultural minorities, adherence, and hypertension. Few cross-cultural studies consider adherence to hypertension recommendations and of those that do, the majority involve African Americans. Poor adherence for African Americans with hypertension has been found to be related not only to individual patient characteristics but also to health disparities and access to services (Ibrahim, 2003). Also, individuals who face barriers to health care (e.g., poverty or difficulty accessing services) are less likely to adhere to treatment recommendations (Hill et al., 1999). Such findings align with the SDOH literature.

Studies conducted with other ethnic minority groups in the USA have also found cultural differences in perception, awareness, control and treatment of hypertension. For instance, a study of Korean Americans, a culture that is reputed for honouring and respecting authority in relationships, highlighted that it was culturally inappropriate for Korean patients to discuss unpleasant side effects of antihypertensive medications with their physicians (Kim et al., 2007). Kim and colleagues (2007) posited that such discussions would challenge the physician's authority and be considered disrespectful.

These differences may not be unique to Korean Americans. Sudano and Baker (2001) noted that Hispanic people living in the USA have a reduced awareness of hypertension. The authors hypothesize that such decreased awareness may be the result of perceived racism from health care providers as well as a lack of provision of culturally-sensitive services. Moreover, treatment for hypertension in Hispanic communities generally consisted of a combination of folk medicine with biomedicine; advice from Western physicians alone was deemed insufficient (Sudano & Baker, 2001).

Health providers' ability to communicate well with patients is a strong predictor of medication adherence (Roumie et al., 2011; Zolnierek & Dimatteo, 2009). Culturally specific health programs can bridge cultural or communication barriers within the health care system. In working with older Chinese immigrants to control hypertension, researchers found that a translator was vital to having the patients' needs met properly (Li et al., 2007). Also, high rates of smoking among older Chinese men was also strongly associated with blood pressure, and culturally-sensitive smoking cessation programs were identified as necessary for this populations (Li et al., 2007).

Another study in the USA involving African Americans and Hispanic Americans found that poor diet played an enormous role in the development of hypertension (Horowitz et al., 2004). The authors recommended that health care workers be aware of cultural variations in diet and that merely prescribing "dietary changes" may not be simple or straightforward to execute. They discussed how the cost of cooking healthy foods, cooking for others, traditional foods and customs, and the importance of food in Hispanic family life were barriers to changing one's diet (Horowitz et al. 2004).

Aboriginal Peoples and Adherence

The dearth of studies relevant to Canadian Aboriginal peoples and adherence to treatment recommendations warrants the need for the present study. For Aboriginal people, it has been well documented that cultural barriers can alter health care encounters. Specifically, minimal eye contact, use of silence, and metaphoric story-telling are deemed more common in Aboriginal cultures, and are strategies physicians can adopt to help Aboriginal patients feel more comfortable during health care encounters (Kelly & Brown, 2002).

Similarly, Abbott (1998) noted that health disparities, ethnic differences between patients and health care providers, socio-cultural issues, access, and communication or language difficulties were barriers to accessing health care and adhering to treatment advice for Aboriginal peoples. One study of Aboriginal peoples and medication adherence for HIV/AIDS concluded that the impacts of colonialism, poor communication with physicians, and cultural barriers affect peoples' willingness to access Western biomedical health services (Hamil & Dickey, 2005).

Unfortunately, accounts of racist encounters and unfair treatment of Aboriginal peoples in Canadian health care are well documented (Billie Littlechild, Este, Galabuzi, & Bassey Etowa, 2011; Canadian Medicine News, 2009; Elliot & deLeeuw, 2009; Hamil & Dickey, 2005; Stephens, 2009; Towle, Godolphin, & Alexander, 2006).

Research conducted with an Ojibway community in Manitoba found that the beliefs surrounding hypertension and diabetes informed how people coped and oriented toward treatment for such conditions (Garro, 1988; 1995). Both hypertension and diabetes in this community were understood as "white man diseases," meaning that they were introduced in the post-colonial era, and that when Aboriginal people lived in more traditional ways such diseases rarely existed. Because the prevalence of these diseases has skyrocketed during the past decade, most people have gravitated toward a societal rather than to a hereditary hypothesis for hypertension and diabetes (Garro, 1995; IPHRC, 2006). For diabetes, poor diet (excessive sugar consumption) or excessive alcohol consumption were deemed to be primary causal factors. Further, a change from traditional foods (i.e., wild foods from the land) to pesticide and chemical-laden foods ridden with preservatives has altered peoples' health and caused this rise in diabetes (Garro, 1988; 1995).

In contrast to the lifestyle-based causes attributed to diabetes, the Ojibway community members identified emotions as the most common cause of hypertension, namely anxiety and stress. Almost all respondents indicated that when they were upset about something their “blood would rise” (Garro, 1988). This aligns with current evidence indicating the relation between stress and hypertension (CHEP, 2012; Kershaw, 2010; Yan et al., 2003).

On other occasions, the community’s beliefs toward hypertension contrasted and varied from traditional biomedical understandings. For instance hypertension was understood as an episodic rather than a chronic condition. Moreover, hypertension was not viewed as an asymptomatic disease; instead, symptoms were perceivable and localized to particular bodily regions, and the result of an emotional imbalance needing equilibrium (Garro, 1988).

From this cultural understanding of the illness, symptoms are to be treated; without symptoms, no treatment would be required. This understanding contrasts with the biomedical model which proposes that hypertension is often asymptomatic and, left untreated, could lead to serious health consequences, including death. Therefore, it is conceivable that different courses of treatment may occur. Biomedical best treatment practices advocate for sustained and consistent adherence to antihypertensive medication, regardless of symptoms being present. However, adhering to treatment only with the presence of symptoms poses many risks as symptoms may present only when the condition is reaching hypertensive crisis.

Garro’s work (1988) is the only known research examining Aboriginal people’s perceptions of hypertension and adherence to treatment recommendations. However, the study is localized to a particular group of people in Manitoba and is more than 24 years old (Garro, 1988). Given the significantly higher rate of CVD, diabetes, and hypertension in Aboriginal

peoples as compared to the overall Canadian population, it is essential to resume this investigation in other settings.

Aboriginal Worldviews of Health

Health worldviews are an overarching way to understand health. These worldviews are based on concepts, theories, or images of health, one's culture, personal belief system, assumptions, and shared ways of knowing (Turton, 1997). They are localized to a particular time and space and continue to evolve. A study of Saskatoon's inner city residents discussed beliefs about traditional Indian healers versus the Western biomedical system (Waldram and Layman, 1989). All respondents in the study reported that they felt certain types of problems (e.g., emotional or spiritual problems) were better handled by Indian healers than Western doctors. Although this study is somewhat dated and incorporated both Aboriginal and non-Aboriginal residents, these beliefs may still exist today.

In addition, the NAHO poll (2002) found that almost 70% of Aboriginal respondents would be more willing to access traditional healing if it could be accessed and subsidized by the Canadian health care system, rather than by traveling and paying for it on their own. These are important findings for health policy or decision-makers to consider when assessing treatment options for hypertension.

Moreover, many Aboriginal peoples in Canada describe health as multi-dimensional and holistic as it combines mental, physical, spiritual, and emotional elements (CIHI, 2004; Hunter et al., 2006). When these four elements are in balance, health is achieved. Similarly, treatment of illness or disease must be approached holistically, and incorporate all elements in treatment to create the desired balance (Hunter et al., 2006). Aboriginal models of health emphasize wholeness, harmony, interconnection, balance, and interrelatedness (Arnold & Bruce, 2005). It is

understood that psychological and emotional trauma due to past colonialism and residential school experiences leads to physical disease (IPHRC, 2006). As a result, the medicine wheel is often used as framework for health and healing (Mussell, 2006). The four quadrants of the medicine wheel represent many things (e.g., the four directions, four colors, four races (humankind), four animals, etc) and, in relation to health, they represent emotional, physical, spiritual, and mental capacities, where the four quadrants can be either in or out of balance. If one quadrant is deemed to be unbalanced, the whole circle or wheel becomes unbalanced.

In attempting to merge biomedical notions of categorization and scientific understanding of causality of health with traditional Aboriginal understandings of health as holistic, Morley (1987) described four categories of causation to assist in understanding disease. The first category is *immediate causes* where cause and effect relationships help explain the problem. For instance, a hot fire results in a burn. Next, *non-supernatural causes* expand on immediate causation by postulating that additional reasoning occurs for things we cannot directly observe. In this case, we appreciate how a virus develops and results in illness, despite it being unobservable to the human eye. Correspondingly, Garro (1988; 1995) found that diseases were explained in various ways depending on the attributions of causality, such as poor diet or excessive alcohol consumption in the onset of diabetes. Both of these causal explanations are lifestyle modifications which prompt individuals to seek services from a Western physician. Such individualized approaches are frequently implemented in biomedicine and health promotion (Morley, 1987).

The latter two of Morley's (1987) categories of causation are often disregarded in biomedicine. The third category, *ultimate causes*, includes both unobservable and immeasurable causes of disease. *Ultimate causes* are frequently treated using alternative medicines, such as

homeopathy or acupuncture. For instance, bio-energy disruptions caused by excessive stress or noise pollution would be deemed an *ultimate cause*. *Supernatural causes*, constituting the final category of causation, involve direct contact with the spirit world. According to some Aboriginal belief systems, a physical disease may result from an emotional or spiritual imbalance rather than solely by something physical or biological (Arnold & Bruce, 2005; Morley, 1987). Such explanations align with a medicine wheel framework (Arnold & Bruce, 2005).

Garro (1988; 1995) described that “bad medicine” –illness resulting from wrong or evil actions-- is treated by an Elder who may communicate with the spirit world to remove the evil. Common practices used for healing *supernatural* and *ultimate causes* may include sweat lodge or pipe ceremonies, prayer, dances, smudging, herbal medicines, fasting, storytelling, teaching, and sharing circles (Poonwasie & Charter, 2001; Turton, 1997). Such practices are deemed to be effective in promoting health for Aboriginal people in Canada (Arnold & Bruce, 2005).

Since many Aboriginal cultures emphasize implicit teachings through oral traditions, such as storytelling (also known as legends or myths), many beliefs about health have been transmitted through oral traditions (Arnold & Bruce, 2005; Turton, 1997). Also, healing may not occur at the individual level. Instead, healing may be more collective and involve families or entire communities (Poonwasie & Charter, 2001). Notably, traditional healers or Elders are considered an important part of healing and tend to be identified by each Nation or cultural group.

In sum, different views of health, healing, and treatment may cause barriers for Aboriginal people who are accessing health services that are largely dominated by a biomedical focus (Arnold & Bruce 2005). In 1997, 80% of Canadian Aboriginal peoples indicated that health and well being is better addressed by traditional Aboriginal, rather than biomedical,

approaches (CIHI, 2004). Nonetheless, many Aboriginal people feel very comfortable accessing biomedical and traditional forms of healing in combination (Turton, 1997). Therefore, health professionals are encouraged to consider culturally-sensitive approaches to treatment and also to acknowledge that individuals may hold different cultural beliefs about health and medicine (Hunter et al., 2006).

In Saskatoon, only 5% of urban Aboriginal people surveyed as part of the Bridges and Foundations Project on Urban Aboriginal Housing self-identified as exclusively practicing Aboriginal spirituality, consisting of the aforementioned practices, including sweat lodge ceremonies and smudging (A. B. Anderson, 2005). It is worthwhile noting that many Aboriginal people do not see religion or spirituality as mutually exclusive, and although they may self-identify as Roman Catholic (38%) or Protestant (22%), doing so does not preclude them from practicing traditional practices (A. B. Anderson, 2005). Nonetheless, maintaining traditional practices in an urban setting is increasingly challenging, particularly given the reduction in Aboriginal languages being spoken in the home (A. B. Anderson, 2005).

As a result of the diversity among Aboriginal people, there are many Elders and traditional healers in or near Saskatoon; yet they may not serve the needs of all Aboriginal residents as they may act in accordance with specific traditions from their own Nation or group. No overarching “Aboriginal view of health” exists; instead there is much diversity and variability within and among Aboriginal persons.

Conclusion

This review is a summary of the relevant literature available to date and a portrayal of the current epidemiological knowledge of hypertension and Aboriginal health in Canada. Inherent in statistical reports of health status are percentages of the prevalence and incidence of disease as

well as mortality rates of Aboriginal peoples. Unfortunately, statistics can present the deficits and offer a negative portrayal of the current health status of Aboriginal people today (Arnold & Bruce, 2005; Statistics Canada, 2001). As such, these data may lead to an assumption that all Aboriginal people have poor health. This assumption fails to present the strengths, resilience, and inherent capacities of Aboriginal people.

Shifting the focus to the strengths of Aboriginal communities (also known as a strength-based approach) enhances self-determination and empowerment while simultaneously building capacity, autonomy, and confidence. Emphasizing strengths is inherent in participatory and action research that engage with communities. Such strategies are highly recommended in any research involving Aboriginal peoples and are necessary in presenting a balanced and more accurate portrayal of Aboriginal health in Canada (CIHR, 2007; IPHRC, 2004). As such, I aim to highlight the strengths of the respondents along with barriers and challenges to health.

In this dissertation I present a much-needed addition to the current literature on Aboriginal health and hypertension. Hypertension remains a growing concern in Canada and poses significant health risks for CVD, stroke, and diabetes. Since Aboriginal people in Canada are experiencing greater rates of hypertension (and its risk factors) than their non-Aboriginal counterparts, it is essential that beliefs and attitudes of Aboriginal persons about hypertension and its treatment be examined.

It is evident that multiple understandings of health exist. Yet the dominant discourse of health remains largely biomedical—a discourse that is perpetuated by Canadian society, the media, and the current health care system (Arnold & Bruce, 2005). For Aboriginal peoples, barriers to accessing health services can be fueled by this dominant discourse.

Despite calls for modifications to current interventions and services in order to better meet the needs of Aboriginal people, such modifications remain unclear. We know that health is best promoted by involving community input and engagement in the creation, delivery, and evaluation of health care programs and services (Newbold, 1998). However, it is unclear whether urban Aboriginal people align with a biomedical and/or an Aboriginal framework for understanding health. Consequently, in this dissertation I, as an outside researcher, have engaged with individuals from the urban Aboriginal communities of Saskatoon to elucidate both their understandings of health in the context of hypertension and their suggestions for improving current treatment and service delivery.

My desire to promote equality between myself and the Aboriginal respondents and to adhere to ethical research standards (CIHR, 2007; IPHRC, 2004), along with the knowledge that involvement of respondents in the design, implementation, analysis, and dissemination of the research best fosters improved health status and empowerment, resulted in my choice of action research as an appropriate methodology, as detailed in the next chapter.

Chapter 2: Methods and Procedures

In this chapter, I present the theory, methodology, methods, and data analytic procedures that I chose in order to conduct this research.

Primary Issue

The primary issue is that hypertension in Aboriginal peoples in Canada is on the rise, and the age of onset is striking earlier in life. Yet, little is presently known about how hypertension -- diagnosis and treatment-- is perceived by urban Aboriginal peoples currently diagnosed with the disease. Overall, urban Aboriginal peoples' health merits a more concerted exploration to better understand the current issues and barriers to care. Such understanding might foster the development of prevention programs tailored to meet the needs of members of these communities.

Purposes of the Study

One purpose of the present study is to invoke Aboriginal people's perspectives on hypertension. My hope is that the stories told by urban Aboriginal people respondents will help to identify their various attitudes, beliefs, and approaches toward hypertension diagnosis and treatment recommendations. As Aboriginal research both in Canada and worldwide has traditionally perpetuated colonialism and advanced only the academic agenda, it is essential that fair and sensitive research adhere to contemporary ethical guidelines for research with Aboriginal peoples (see Ethics for Research Involving Aboriginal Peoples section) and incorporate the views and input of the community (National Aboriginal Health Organization [NAHO], 2007). Further, community-based research promotes community engagement with the research, thereby fostering and developing community capacity in a mutually beneficial manner (Smith, 1999). Therefore, a second purpose of the study is to engage with the Aboriginal

communities to promote health and awareness of hypertension in a way that meets the communities' needs.

Defining communities. The term *communities* is frequently mentioned throughout this dissertation. I define a community in a very particular way -- as a social network of individuals who feel connected and are working toward a common goal or purpose. In this case, the common purpose and connection may be loosely based on being part of an ethnic/cultural minority group within an urban setting. Given that Aboriginal peoples in Saskatoon are ethnically and culturally diverse, the term *community* will be referred to in the pluralized form, *communities*. Moreover, the communities are not defined by fixed geographic boundaries, since Saskatoon's Aboriginal people are distributed around the city and do not constitute the majority in any particular neighbourhood (A. B. Anderson, 2005). Despite this distribution around the city, Aboriginal people are predominantly located on the west side of Saskatoon. For the present study, the Aboriginal communities constitute all Aboriginal persons residing in Saskatoon who self-identify as such.

Research Questions

The following questions form the basis of this dissertation: how is hypertension understood and experienced by Aboriginal peoples? What changes need to be made to improve rates of hypertension in Saskatoon's Aboriginal communities? What is the most effective manner to create these changes?

Rationale for Qualitative Research

There are many possible quantitative and qualitative ways of conducting this research. I chose to conduct a qualitative study as I deemed it the best fit for this project and considered various arguments in coming to my decision. I first explored, from the perspective of a non-

Aboriginal person, the idea of trust with Aboriginal communities. Specifically, research done “to” Aboriginal peoples has often taken the form of helicopter research (i.e., the researcher flies in, collects data, and leaves, offering nothing more to the community) or actually inflicted harm upon the community (i.e., removing cultural treasures, artwork, sacred items, or medicines, and deceiving the people as to why the information was collected). Consequently, Aboriginal communities are, rightfully, skeptical of research, and trust needs to be established prior to research approval being granted (Smith, 1999). Trust takes time and is best established when the researcher becomes familiar with individuals in a community. Dickson (1997) thoroughly described her efforts, as an outside researcher, to integrate into participatory action research with Aboriginal women of Saskatoon. My chosen style of qualitative research helps foster trust, as individual wisdom and community values are honoured. Through direct engagement with the respondents and the Aboriginal advisory group, I strove to continuously demonstrate that I had good intentions in conducting this research. I approached the project not as something to accomplish, but rather as an immersion into learning about the local Aboriginal communities. Therefore, I engaged with the local Aboriginal communities in ways beyond traditional research protocol. For instance, I attended sweat lodge ceremonies and volunteered as a board member of a student-managed primary health centre in the core neighbourhoods of Saskatoon. I selected such initiatives in an effort to better understand the communities and some of the struggles they face. The process of becoming accepted into Aboriginal communities varies; however, it is evident from my experience and that of other outside researchers having conducted similar work that this process takes a considerable amount of time, energy, and willingness to go beyond traditional positivist approaches to research.

Secondly, it is imperative that research involving Aboriginal peoples be conducted ethically and with utmost cultural sensitivity (Smith, 1999). Guidelines for conducting research with Aboriginal peoples include the notion of understanding and respecting local knowledge and perspectives, as well as the active involvement of the community at all stages of the study to ensure that everyone involved benefits (Canadian Institutes of Health Research [CIHR], 2007). Such participatory and action-based methodologies are typically qualitative, although not necessarily.

In sum, a qualitative research approach was the most appropriate form of research for my study as it enabled me to gather in-depth interview data from which I could more clearly grasp the respondents' perspectives and worldviews on health and illness. Instead of examining survey numbers or statistical output as my data, I wanted to hear the rich and diverse stories through direct engagement with the respondents. As such, using a qualitative framework was a suitable way to conduct this research.

Epistemological Position

My epistemological stance falls between two very common positions --positivism and constructionism. Positivism is an epistemological way of knowing that bases truth on material and objective reality. It strongly values objective, empirical evidence that is measurable, and aligns closely with contemporary science. Positivism, then, contrasts with notions of subjectivity derived from emotions or perceptions (Crotty, 1998). My study involves positivist notions, in that I acknowledge that hypertension is a real, physical entity. It can be measured and it can be studied as a biological and medical truth.

Nonetheless, my study also involves constructionist positioning. The definition of constructionism varies depending on the source or author; however, for the purposes of my

dissertation, constructionism is defined as an approach to knowledge as subjective or framed within a particular, and relative, context (Burr 1995). As such, individuals construct their reality through their experiences and position in society. When applied to the present research, the experience of having hypertension is entirely dependent on how the beholder interprets or makes meaning of hypertension regardless of how biologically measurable hypertension may be in the human body.

I argue that although my understanding of the research data involves both positivist and constructionist notions, it is best approached from a critical realist epistemology. Critical realism involves a balance between the two common epistemological positions, positivism and constructionism. This position posits that reality consists of a “material dimension,” similar to that found in positivistic explanations of knowledge (Sims-Schouten, Riley, & Willig, 2007). However, with the notion that context is everything positivistic science is critiqued for being limited and constrained. Further, in critical realism, this material understanding of reality combines with human influences such as one’s personal and social context. Critical realism posits that some reality is not explainable by statistics; instead we need to use a critical eye and understand that the nature of reality lies in a multitude of layers rather than a straightforward cause and effect relation.

Of particular relevance to this study, critical realism places greater emphasis on the structure of institutions, a dimension frequently neglected in both positivism and constructionism (Sims-Schouten, et al., 2007). The structure of institutions examines the power relations embedded within large-scale institutions such as hospitals, universities, prisons, and so forth. Critical realism has the capacity to orient to a variety of theoretical perspectives, methodologies, and methods.

Theoretical Perspective

In the current body of evidence-based literature on hypertension and/or Aboriginal health, no published information exists regarding how urban Aboriginal people experience and view hypertension⁴. As a result, I am drawing on existing broad-based theories to help interpret the data. As my goal for this dissertation is empirical -- rather than theoretical -- I am attempting to contribute to the scarce knowledge and subsequently enhance awareness of hypertension in the Aboriginal and non-Aboriginal communities of Saskatoon. Such efforts are aimed at facilitating change and promoting health within the local context, both of which benefit from an explicit theoretical standing.

The present research is most influenced by critical theory which challenges taken-for-granted notions of why people are afflicted with diseases, and looks at deep-rooted and societal-based causes of health and illness. Such causes are explored through the lens of historical, cultural, political, colonial and socio-economic forces that mediate the understanding of the material and somatic experience of hypertension for Aboriginal peoples.

My dissertation, as is the case with all research, is inherently political. Through my analysis, I challenge and critique the status quo. Critical theory guides me to explicitly state my political assumptions and deliberately analyze the politics entrenched in health issues, thereby emphasizing notions of oppression and dominance within health and biomedicine. In subsequent chapters, I elaborate on the ways that power structures are embedded in the Canadian health care system, as they are similarly embedded in all social structures that originate from a white, colonial and imperial system.

⁴ The only known research examining hypertension and Aboriginal people by Garro (1988) was conducted with a reserve community rather than with urban Aboriginal peoples.

The critical theorists whose works inform the present research originated from the Frankfurt Institute of Social Research, better known as the Frankfurt school. The Frankfurt school consisted of a group of elite scholars trained in Marxist philosophy who met regularly during the 1920s and 1930s to debate and critique capitalist modernity. These intellectuals expanded on Marxist and Weberian ideas of social class and institutional power to include existentialist, hermeneutic, psychoanalytic, and constructionist influences (Edgar, 2006). Some of the more renowned intellectuals associated with the Frankfurt school include Horkheimer, Adorno, Marcuse, Lowenthal and Pollock. As a result of the changing political climate during World War II, the Frankfurt school and its philosophers went into exile, for fear of death for their radical and non-conventional philosophical ideas. Post-war, the work of the critical theorists expanded to become much more broad-based, more philosophical, and less dogmatic than before, and was considered the Frankfurt school's second generation.

During the mid-1980s, Michel Foucault, a well-known French philosopher, further developed and enhanced what is now deemed to be post-modern critical theory. He included notions of culture as influencing societal discourses and posited that power is an inevitable aspect of social life. Contemporary adaptations of critical theory continue to challenge the status quo and power relationships within institutional structures in society. Such adaptations evoke analysis of additional societal influences (e.g., culture and media) in understanding social science, human experience, and health. In deliberately highlighting the role of power and colonialism within health care encounters with Aboriginal patients, I hope to reveal barriers that are not typically included in health psychology research.

The main tenets of critical theory, according to Morrow and Brown's version (1994), include:

1. “Science and technology cannot be fully neutral with respect to human values because they inevitably mediate social relations” (p. 63).
2. “Dominant political and social interest shape the development of science and technology, hence the autonomy of science is problematic” (p. 63).
3. The goal is “radical socio-political transformation” (p.12).

The “critical” in critical theory does not mean negativity; rather it is critical in that it is challenging the nature of reality, knowledge, and explanations. Further, it involves ongoing self-reflexivity with the research data and cultural discourses, meaning that the researcher constantly reflects on his/her role within, and influence upon the data. Further, the researcher engages in a personal critique, examining one’s biases, and assumptions and subsequent impact on the research process. As such, critical theorists frequently draw upon their ability to engage in self-reflexivity during the research process. It is not research from a distance, but instead from a researcher’s lived experience.

Critical theories complement critical health psychology, medical sociology, action research or other emancipatory-focused research paradigms (Edgar, 2006; Haverkamp & Young, 2007). The goal of critical theory is to expose and reveal deeper political, economic, and power agendas within the social world. Overall, critical theory can be applied to micro and macro levels of physician-patient encounters and lay versus expert knowledge, topics on which my future chapters elaborate.

Although psychology offers much to, and broadens the scope of, health and medicine, scholars are identifying that mainstream health psychology’s predominant focus on the biopsychosocial model is limited in its capacity to explain health behaviour (Crossley, 2001a; 2001b; Murray, 2004). Similarly, when conducting health research cross-culturally, particularly

with oppressed cultural groups, it would be a disservice to abandon critical approaches which, by virtue of the theory, incorporate cultural understandings of health (Crossley, 2001a; 2001b; Murray, 2004). Consequently, critical health psychology is gaining prominence, particularly in Europe and globally in qualitative research circles. Because of this emphasis on culture and other societal-based forces such as history, socio-economic status, and politics, I deemed critical theory to be a fitting frame for this dissertation.

As critical theory has been criticized for being nothing more than an intellectual exercise, it pairs nicely with action research. According to Michelle Crossley, it is unethical to understand oppressive structures and not do something to try to intervene to improve the situation (Crossley, 2001a, 2001b). Critical theory has been criticized for being too rational and not emancipatory enough in its focus, therefore coupling with an action research methodology that is oriented to community betterment, addresses this critique.

In addition, critical approaches intersect with Indigenous approaches as both emphasize the “political and moral” nature of inquiry (Denzin & Lincoln, 2008, p.2). Critical approaches and methodologies are political, liberatory, emancipatory, and reflexive (Denzin, Lincoln, & Smith, 2008; Lather, 2007). Similarly, Indigenous approaches and methodologies are “research by and for Indigenous peoples, using techniques and methods drawn from the traditions and knowledges of those people” (Evans, Hole, Berg, Hutchinson, & Sookraj, 2009, p. 894). These two unique forms of inquiry pair well together as they both examine the effects of power, oppression, and colonialism on people living in unjust realities (Denzin et al., 2008). However, unless participatory approaches (with community involvement) are included in the union between critical and Indigenous approaches, this fusion of research will remain colonial and continue to emphasize the learned academic person speaking for the underprivileged “other”

(Denzin & Lincoln, 2008, p.5; Evans et al., 2009). Despite previously seeming at odds, critical and Indigenous approaches are frequently being fused together to create meaningful research with Indigenous peoples worldwide (Denzin et al., 2008; Evans et al., 2009).

As I recognized early on that conducting research involving urban Aboriginal communities was complex and that there were many factors influencing biomedical health status beyond what most health promotion projects emphasize, I deliberately selected critical theory as the most appropriate foundation for this dissertation. In doing so, I am able to examine power and colonial relations within health care, topics frequently neglected in health psychology research. Further, critical theory best allowed me to incorporate contemporary understandings of health as dynamic and greatly influenced by external factors, such as the social and Aboriginal determinants of health (NAHO, 2007; Public Health Agency of Canada [PHAC], 2004). Overall, critical theoretical perspectives best allow me to address issues relating to the role of power relations embedded in health institutions, the controlling of health resources and medical knowledge, and health disparity among urban Aboriginal peoples in Canada.

Methodology

Participatory action research. It is necessary to define and elaborate on participatory action research (PAR) prior to explaining the methodology that I have chosen for this study, action research. Specifically, action research is a sub-form of PAR and to adequately explain it, it is important to understand its origins⁵.

⁵ I refrain from describing the present research as *participatory action research* despite my efforts to maintain community participation throughout the research process. My hesitation derives from the principle that PAR, in its ideal form, is typically an extended commitment to working with a community, whereas this project was in the context of a time-limited doctoral dissertation. Knowing that my clinical psychology doctoral training program concludes by my leaving the city to conduct a residency, my ability to maintain a committed and dedicated relationship with the Aboriginal communities of Saskatoon was compromised from the outset.

Two distinct methodologies, *participatory research* and *action research*, fuse to form PAR (Barnsley & Ellis, 1992). Simply put, *participatory research* involves respondents as co-researchers, whereas *action research* strives to create change for people. PAR, introduced by Fals-Borda (Fals-Borda & Rahman, 1991), became extremely popular in agriculture and other industry during the late 1970's (Whyte, 1991). It evolved out of social research methodology and had its origins in anthropological and sociological research in developing countries (Park, 1993; Whyte, 1991). In part, what distinguishes PAR from other methodologies is that the researcher and the respondents are co-researchers. The researcher contributes certain skills and knowledge and the respondents equally contribute their own expertise, knowledge, and understanding of their social world.

Further, in mainstream research projects, a study's design and methodology are often created to benefit a researcher or the academic institutions, yet do not deliberately attempt to benefit the respondents or larger community. In contrast, PAR involves the researcher partnering with community members (and ideally all the stakeholders) to create research where everyone benefits (Park, 1993). The entire process of the research is discussed and collectively agreed upon by all those involved. Furthermore, the commitment to the relationships with the

For the purposes of conducting research with integrity and honesty, and being realistic and practical with myself and the respondents, I chose, instead, to implement an action research methodology which incorporates participatory involvement as much as possible, but is not dependant on full participation from the stakeholders at every stage for its completion. To meet the demands of a doctoral dissertation, some aspects of this project were required to be my own original contribution. As such, I believe that an action research methodology allowed me the opportunity to conduct a fair, ethical, and empowering research project in partnership with the Aboriginal communities while still meeting the degree requirements. Regardless of the chosen methodological name, I am deeply committed to the betterment of the respondents and the communities. As a result, I have attempted to ensure that the momentum of the project is sustained long after my departure from the city, including having ongoing involvement with the Aboriginal advisory group and meaningful dissemination of the results.

stakeholders or community members is typically not limited to one research project; it is a life-long commitment to work together with that community or set of partners.

As such, PAR has been identified as one of the most ethical ways of conducting research with Aboriginal communities as it ensures the community is involved, trained, and satisfied with the research at all stages of its development (CIHR, 2007; Indigenous Peoples Health Research Centre [IPHRC], 2004). Rather than the researcher selecting this methodology, it is Aboriginal communities that are demanding that ethical research be conducted (IPHRC, 2004; Smith, 1999).

PAR also involves an action component; specifically, the end goal is to achieve some type of change for a community, as decided collectively by the researcher and community (Park, 1993). Respondent involvement in research tends to foster a greater investment in the outcome. This investment leads to a sense of empowerment for the co-researchers (respondents) and ultimately the community. Moreover, it is a goal of PAR that a community learns how to create action; such capacity building then enables them to further a project or have the tools to take action in the future. As such, PAR places greater emphasis on process than outcomes. PAR essentially aims to build capacity within communities that may have felt oppressed, neglected, or ignored by mainstream society. The researcher learns as much from the respondents as they do from him/her.

Action research. Action research was the chosen methodology for this dissertation for several reasons. First, in line with national and international ethical guidelines as well as Aboriginal research trends (to be explored in greater depth later), those conducting research with vulnerable or minority groups are encouraged to work with, rather than work on a community. This collaborative approach allows the community's agenda to be paramount. As numerous

Aboriginal communities have expressed their frustration of being the subject of countless research studies, I felt that action research was the most suitable methodological choice.

Action research, a sub-form of PAR, is defined as “a systematic participatory approach to inquiry that enables people to extend their understanding of problems or issues and to formulate actions directed towards the resolution of those problems or issues” (Stringer & Genat, 2004, p.4). Action research is the most common form of intervention research used in education today, and it is becoming much more common in health care settings (Johnson, 2005; Meyer, 2006; Stringer, & Genat, 2004). Although it is less common in health psychology, nursing research is replete with examples of its effectiveness in health care settings. Johnson (2005) and Crossley (2001a, 2001b) argued that to conduct appropriate health interventions, we need to grasp the underlying social, political, and other deep-rooted issues. Bridging research and practice is what action research essentially strives to do: create meaningful, evidence-based change. This aligns with current trends in health research to translate and disseminate knowledge (CIHR, 2007).

Action research is typically conducted from a constructionist epistemology, yet it may also be conducted from a positivist epistemological position. Methodologies and methods are also diverse and may involve quasi-experimental designs, survey questionnaires, or qualitative methods such as in-depth interviewing or naturalistic observation. Any method is feasible in action research as long as power and control is shared by the stakeholders and the researcher (Gibson, Gibson, & Macaulay, 2001; Meyer, 2006; Stringer & Genat, 2004).

It pairs with a variety of theoretical orientations, yet action research most often is associated with critical and qualitative approaches (Crossley, 2001a, 2001b; Haverkamp & Young, 2007; Stringer & Genat, 2004). For some time, action research was viewed as incompatible with critical theoretical perspectives. A paradox inherently exists between

observing power structures versus trying to alter the power imbalance in health (Johnson, 2005). It was understood by scholars in both areas that modifying social injustice and power imbalances requires changing their structure. Therefore, the approach to research was seen as having different aims: commenting on the deeper levels of political, economical, societal, and historical impacts on health or attempting to modify at those levels. This division remained for years between the hard and soft researchers: the theorists and the philosophers versus the community-focused and grassroots researchers, respectively (Johnson, 2005).

However, this tension is being dissolved as critical health psychologists are witnessing, from other health disciplines, the benefits and possibilities of merging critical theory and action research. Similarly, action research promotes constant reflexivity and self-critique (Johnson, 2005). In sum, I argue that a critical theoretical framework, action research methodology, and methods consisting of individual interviews and a focus group are most suitable for this dissertation.

PAR is explicitly ideological, and arose out of class struggles and agricultural revolts in developing countries (Whyte, 1991). Although action research can also be political in nature and promote political activism, it tends to be quite practical and concrete in terms of executing a change or solving specific problems. One of the aims of action research is for respondents to advocate for their needs, while simultaneously being partners in the project and building each individual's and the community's capacity and skill base (Gibson et al., 2001; Meyer, 2006). The emphasis is placed on transformation and empowerment fostered by enhancing knowledge, awareness, and understanding.

Action research is based on the same principles as PAR, i.e., to engage the local community to improve people's lives. The focus of action research is on a specific and particular

context rather than on global understandings or generalizations of knowledge (Stringer & Genat, 2004). It is less political and ideological overall; action research is mainly focused on promoting a sense of community by engaging people in something that is meaningful to them. Aboriginal people are not always asked to engage with their experiences as patients and reflect on possibilities or notions for change within the health care institutions, however, calls have been made to ensure Aboriginal research emphasizes such capacities (CIHR, 2007; IPHRC, 2004; Smith, 1999).

Taking these priorities into account and to properly execute action research, this research attempts to engage with participants⁶ from the communities at every stage of the research from the development of the research questions to the data collection, analysis, and dissemination process (Gibson et al., 2001; Stringer & Genat, 2004). Since this project is limited by the constraints of a dissertation, my long-term involvement remains mainly with the Aboriginal advisory group.

Further, in action research a significant emphasis is placed on disseminating the research findings to the respondents and the community involved (Stringer & Genat, 2004). Methods of dissemination include communicating findings formally (written reports or presentations), creatively (i.e., photovoice, poetry, documentaries, or theatre performances) or practically (e.g. program evaluation, community development, professional development, or health promotion) (Stringer & Genat, 2004).

In health care, common ways to disseminate action research findings include: improving health outcomes by helping in the development and implementation of personal care plans,

⁶ The term *respondent* is used to describe the Aboriginal individuals diagnosed with hypertension whom I interviewed. The term *participant* is used to describe all individuals who took part in the study (i.e., respondents and members of the Aboriginal advisory group).

learning new and innovative ways to live and cope with illness, working with communities or agencies to address public health concerns, and setting quality assurance standards in service delivery (Stringer & Genat, 2004). Formal health research dissemination can occur through policy recommendations, formal reports, documentaries, or health promotion (Stringer & Genat, 2004). Regardless of the method of dissemination, the knowledge and deeper understanding that is typically gained through the dissemination of the research tends to be a reciprocal learning experience for both the researcher and respondents (Gibson et al., 2001).

In sum, an action research methodology goes beyond the mere collection of information by providing communities with the relevant knowledge and understanding while honouring the interests of the communities involved (Gibson et al., 2001; Stringer & Genat, 2004).

According to Stringer and Genat (2004), typical values that are emphasized in action research are:

- Change (improving practices, behaviours, health status)
- Self-reflection (thinking about own practices, behaviours, situation)
- Participation (involvement of respondents)
- Inclusion (starting with least powerful and moving out to all involved)
- Sharing (perspectives)
- Understanding (appreciating different perspectives)
- Repetition (cycles of research activity)
- Practice (implementing new understandings)
- Community (developing a stronger sense of community or of a learning community)

A large component of action research involves the capacity for the researcher and the respondents to engage in an ongoing process of self-reflection and reflexivity (Meyer, 2006). Therefore, it is vital that, as a researcher, one's assumptions and beliefs be clearly stated. I engaged in ongoing note-taking in the form of field notes and a personal reflections journal. These notes were particularly helpful to return to at various stages of the project for understanding and synthesizing the research process. Likewise, the community is responsible for creating meaningful and practical results (Meyer, 2006). Action research is research in progress; the learning is continuous and ever-evolving as various perspectives are presented. In most traditional forms of research, a researcher comprehensively reviews literature on a particular topic, then engages in data collection, analysis, and reporting the results. In action research, however, the researcher often returns to previous stages of the research, such as reviewing how one's own attitudes might be influencing the interpretation or reviewing the results with the respondents in order to ground the interpretation in meaningful outcomes. In conducting an action research dissertation, I attempted to integrate all of Stringer and Genat's (2004) core values.

Formation of the Aboriginal advisory group. I was able to successfully collaborate with the Aboriginal communities of Saskatoon mainly because I established an Aboriginal advisory group for the present research. Albeit rewarding, this was not, however, a straightforward process.

In 2007, a primary health care clinic in Saskatoon had an existing *participatory working group* comprised of community researchers, community members (mostly Aboriginal), health care workers, and the University of Saskatchewan's family medicine research staff. This group met bi-monthly to discuss and tackle important community health issues. When I first became

acquainted with some members from this group, the participatory working group had recently compiled the results of a community survey. This informal community-based survey was conducted in 2007 in Saskatoon's core neighbourhoods (where the population consists of a high proportion of Aboriginal people) by Aboriginal researchers from the participatory working group (V. Ramsden, personal communication, July 2007). This survey, although not formally released, identified hypertension as a higher priority than diabetes within these communities. As hypertension is a risk factor for diabetes, among other diseases, and the rates are high in the community, the participatory working group identified hypertension as a key area of concern, along with tobacco misuse.

The intent to focus future community-based interventions on hypertension was an ideal fit for my doctoral research, and I began to make arrangements to join the participatory working group and to become connected particularly with the community members and researchers. The plan was for me to join a larger community-based study by adding my interview questions to an already existing interview guide about hypertension. It took nearly two years of meeting with the organizers in order for some of the group members to be willing to trust and meet with me. Throughout this process, I had to be very explicit about my goals. I struggled with feelings of frustration during times when the group members did not respond to my emails, phone calls or requests to meet, sometimes for months on end. In hindsight, it was an excellent exercise in patience--learning to surrender to the communities' agenda, and to realize that my priorities as an academic researcher do not always align with others' priorities.

Going through this initial process was an opportunity for me to relearn how research is conducted in community-based settings and with Aboriginal communities. My formal academic research training concentrated on experimental methods where research conditions are tightly

controlled. Consequently, it was counter-intuitive for me to learn to surrender the control of research, to allow others to direct the process and to stay resolute that action research is beneficial. There were certainly days where I questioned my choices, and critiqued the process extensively, which helped me clarify why I had chosen this methodology.

Over time, though, I realized that the participatory working group's monthly meetings had been cancelled for several consecutive months. When I inquired, I was informed that people were busy, but my intuition told me there was a different reason for the cancelled meetings. Eventually, the group shared with me the details of the situation: there were internal politics and the participatory working group had temporarily disbanded. Such disbandment occurred due to tension between the health care workers and the community members; in addition, the community members had not been adequately compensated for their time and involvement.

Unfortunately, I had already devoted two years to forging relationships with this group and my decision to abandon this group was not taken lightly. This decision was particularly difficult, as I knew the group wanted to address hypertension in urban Aboriginal peoples. In addition, they were the only group to my knowledge that was located within the target communities with whom I had developed trust and rapport, and who actively had community members involved in the research.

Nonetheless, with much reflection, I learnt that the situation was, sadly, quite typical. There remains much racism and hostility between the Aboriginal community and the health and academic institutions. These issues are not new, nor are they unique. I felt saddened by this reality, but was still determined not to give up my desire to conduct community-based research where I engaged with the Aboriginal communities.

For some time, I remain stumped, in limbo, and unsure as to how to proceed. Eventually I scheduled a meeting with an Aboriginal professor with whom I had consulted on many occasions over the past three years. I was aware that she had many connections within the communities. My intentions were to ask for her guidance and suggestions. Specifically, I sought her wisdom on potential other collaborators. During this meeting, however, I was utterly astonished as she mentioned that she would be willing to help me form an Aboriginal advisory group with some very prominent Aboriginal people. She further stated that she would be willing to join this advisory group. As we had many consultations about my project for several years prior to this meeting, she expressed that she knew my intentions were good and that I had earned her trust and demonstrated persistence and willingness to be there for the community in a genuine way. Within a few days, I had a functioning group which we called the Aboriginal advisory group.

The present research project was conducted wholeheartedly in collaboration with the community-based, Aboriginal advisory group. This Aboriginal advisory group served as an external ethical body to oversee and guide the research project and ensure its cultural relevancy and appropriateness. This group provided community consent for the project. Members of this group were affiliated with the Indigenous Peoples' Health Research Centre of Saskatchewan (IPHRC), --one of the centres funded by the Aboriginal Health Research Network Secretariat (AHRnetS) formerly known as the Aboriginal Capacity and Developmental Research Environments (ACADRE) network-- First Nations University of Canada (FNUC), and the Saskatoon Indian and Métis Friendship Centre (SIMFC). This group was well suited to bridge research from an academic institution with the needs of the community. There were four members in the Aboriginal advisory group, including a spiritual Elder, a professor who had recently published a book for Aboriginal social work, a professor and chairperson of SIMFC, and

a community-based Aboriginal researcher; the expertise of the group members was striking. There were two female and two male members of various ages, originating from various First Nations situated across Saskatchewan.

The Aboriginal advisory group also recognized hypertension as an important area of study and indicated commitment to helping with the present research and to working toward the goal of reducing overall rates of hypertension within the local communities. I initially met with each group member individually to ensure each was well informed of the project goals and demands. Next, I scheduled a gathering where the four group members and I met together. I was informed of traditional practices such as always bringing a gift of tobacco for the Elder and all our gatherings commenced with a blessing and prayer from the Elder and burning of tobacco. During the initial gathering, I distributed a research contract, modeled after the CIHR sample contract, (CIHR, 2007) and reviewed how I was committed to addressing potential ethical concerns that commonly arise in Aboriginal research (see Appendix A). I also indicated the goals and objectives of the study, commitment required and timeline, honorariums, and process of collecting, storing, and disseminating the data.

We also discussed consent to participate and confidentiality of respondents, to which everyone agreed. Following this general discussion, the group provided input on my recruitment poster and research questions guide (Appendix B and C). They prompted me to think more broadly about the language I would be using, (e.g., hypertension versus high blood pressure) and the assumptions that the questions contained. The Aboriginal advisory group also encouraged me to put their names directly on my recruitment poster, stating that they had approved the study and would be available for any questions (see Appendix B). Moreover, they encouraged me to put a

culturally-relevant image on the poster and we decided on the images of a medicine wheel and feather.

My engagement and collaboration with the Aboriginal advisory group was immediately beneficial. I strove to ensure that everyone was gaining from this engagement and collaboration; they assured me that they were equally pleased to participate and felt the project was worthwhile of their time and efforts. They noted that they preferred to hold a minimal role, mainly to provide guidance and direction as needed. As long as I maintained respect within the group and with the communities and continued to inform them of my process, they were satisfied.

One of the group members wrote a letter outlining the group's support for the project (see Appendix D). After all these details were finalized, I submitted an ethics application to the university's research ethic's board (REB) along with the letter of support and, upon approval from the REB (see Appendix E) approximately five weeks later, I began the study.

Standards of quality. As with all forms of qualitative research, there are concerns about the rigor of action research since standards of reliability and validity typically applied in the evaluation of positivist research are inappropriate. Instead, concepts of honesty, transparency, and reflexivity are strongly emphasized as measures of quality control (Silverman, 2005).

In action research, quality is a result of the nature of engagement with the community (Viswanathan et al., 2004). With a central focus on dissemination, action researchers are automatically accountable to the respondents who, themselves, also provide feedback and engage in their own process of reciprocity (Meyer, 2006). A study's rigor and validity is primarily determined by the respondents or stakeholders who ultimately determine if the research is useful and impactful. Rigorous research engages people, is impactful, and makes a difference in the society (Stringer, 2007). As such, the dissemination of knowledge should not be solely

performed at the end of the research (Aboriginal Health Research Network Secretariat [AHRnetS], 2006). Rather, the dissemination of knowledge becomes an ongoing process, reflexively undertaken by both researchers and respondents.

Although I formally disseminated the findings, I also attempted to engage the participants in the analysis in an iterative manner throughout the research process. In particular, we engaged with the data and reflexively assessed our roles and understandings of the findings during the focus group. Likewise, I met with the participants from the Aboriginal advisory group to discuss every stage of the research which enhanced my transparency and honesty in the research process.

Reliability in qualitative research is enhanced by the aligning of one's theoretical perspective, research questions, and methodology. My use of critical theory and adherence to guidelines for conducting research with Aboriginal peoples informed my research questions and choice of methodology. All three aspects of research design need to complement each other, be appropriate to the study, and be clearly stated (Silverman, 2005). Silverman (2005) also indicated that transparency in the data collection and analytic methods are important. To satisfy this requirement, I made use of research memos and field notes throughout the process, and reviewed the analysis with the participants.

A final quality standard in qualitative research is transferability. The aim is not to generalize and extrapolate the findings to broader society. Instead, qualitative researchers aim to be deliberately forthcoming about the research process in such a manner that the reader can determine whether the context and experiences are potentially similar to other contexts.

Methods

Individual, semi-structured interviews were the most appropriate method for collecting the majority of my data. My rationale for choosing the individual interview was that having

respondents together in a group setting might either inhibit the respondents' comfort or affect their willingness to disclose personal information. Also, I wanted to hear from each respondent about their own experience with hypertension, their health-care provider, and views for interventions without their being influenced by what other respondents had experienced. I was particularly interested in the range of responses rather than overarching similarities between respondents, as I was cognizant of the diversity among urban Aboriginal peoples in Canada.

Following the individual interviews, the respondents re-engaged with the problem during the focus group, where the analysis was presented and the group reflexively assessed what course of action would best follow. The knowledge generated and ideas discussed from the individual interviews and focus group were used as a catalyst to fuel and inform the action components of the present research that the respondents and the Aboriginal advisory group believed would most appropriately bring awareness and preventive reduction efforts to hypertension in Saskatoon.

Recruitment process. I recruited potential respondents by displaying recruitment posters in safe, comfortable, and accessible locations. I mainly targeted public and community-based settings rather than medical settings to open recruitment to those individuals who might not seek biomedical health services. I also wanted respondents to learn about the study without having to venture into medical venues. The Aboriginal advisory group gave me some suggestions of potential locations to display my recruitment poster.

I placed posters at various sites such as the Saskatoon Indian and Métis Friendship Centre, Saskatoon Tribal Council, Westside Community Clinic, Westwinds primary health care clinic (see Appendix B). I also put up posters at the public libraries, coffee shops, pharmacies, and hospital elevators. I did not expect the overwhelming response I received from local

agencies and the local communities. An electronic version of my poster was requested from the Saskatoon Indian and Métis Friendship Centre. Within hours, they distributed the poster by email to hundreds of community agencies and Aboriginal contacts. Also, the city of Saskatoon contacted me and requested permission to place my call for respondents in the city's monthly calendar. My poster was also distributed through the Indigenous Peoples Health Research Centre electronic listserv.

Once people followed up by phone expressing interest, I returned their calls and briefly described my affiliations and the purpose of the study. I specifically asked the respondents if they qualified for the study (see the screening questions described in more depth in the next section). I was surprised at how quickly I was contacted by individuals interested in participating in the study. Initially, I had been hoping to recruit 6-8 people, but in an effort to accept as many people as possible, I selected 11 respondents. I scheduled respondents on a first come first serve basis.

As with any type of research, there were challenges with the recruitment. Because I was offering an honorarium, I was initially overwhelmed by an excess of phone messages. I was struck by the interest in the study and, as I began to return the phone calls, I realized that some individuals wanted to be involved despite not meeting the study criteria (i.e., having formally diagnosed hypertension, and being Aboriginal). I had to decline some people who did not have hypertension, but wanted to meet me "to talk about [their] lives and get paid."

As a result, I developed the following screening questions 'what is your most recent blood pressure reading?' and 'what medications are you on/have you been prescribed?' This screening procedure had its own flaws in that not everyone is aware of their most recent blood pressure reading, and some may have chosen not to take medications or cannot recall the names.

Nonetheless, a couple of people who responded to the recruitment poster and claimed to have hypertension directly admitted during the screening questions that they did not have hypertension but rather another disease (e.g., FASD, anxiety, or IV-drug use) that made their heart pound vigorously. Of those who did meet the criteria, some wanted their friends to sign up as well or wanted to meet the other respondents to “meet others with high blood pressure.” I came to appreciate the strong emphasis on values of sharing and a sense of community among Aboriginal peoples (King, Smith, & Gracey, 2009; Poonwasie & Charter, 2001).

Overall, I was unable to contact three individuals who had expressed interest in participating as they did not own a telephone and I was leaving messages with a community agency. In addition, there were two individuals whom I was unable to interview who met the screening criteria. After consulting with my research advisor and the Aboriginal advisory group, I decided that I had to make a decision about when to stop recruiting, regardless of how difficult it was to turn people away. In the end, I informed the two individuals that I was no longer interviewing for the study; however I also told them that, depending on the findings, I might recruit participants in the future (e.g., for potential action research projects), and I gathered their names and telephone numbers for this purpose.

Deciding on the appropriate number of interview respondents was a facet of the research that unfolded over time. Initially, with the assistance of my research committee, we decided that a smaller number of individuals (between four and six) would be appropriate as I was not attempting to generalize to the larger population. Additionally, in contrast to quantitative research where the precise research methods are typically known from the outset, I was uncertain to what extent the interview respondents would be involved in action research initiatives or capacity building. Therefore, collectively, we decided that a small sample size was most

appropriate. Nonetheless, I had concerns that it was too few and that I would not have enough data to analyze. As such, after further consultation with my research advisor, I decided that a greater range (from six to ten people) would be more appropriate. This decision was also based on my available resources such as the time and financial investment required.

As I began to interview respondents, I also began transcribing and conducting preliminary analyses. Having the data collection staggered with the analysis allowed me the opportunity to reflect on my findings while I continued to gather more data. Simultaneously, I was able to consult with my research advisor regarding the findings and together we agreed that the participants were incredibly diverse and the interviews I had conducted contained good variability and produced very rich, complex data. We agreed that data saturation had occurred by the time I interviewed the ninth respondent; while I could generate new codes, the overarching themes remained unchanged. As such, we decided I should gather a bit more data as a precaution, and I interviewed two more individuals. The robustness of my themes allowed me to feel confident in the number of interviews that I conducted. Of note, the correct number of interviewees is an ongoing topic of debate in qualitative research (Baker & Edwards, nd).

Respondents. Interview respondents consisted of six male and five female adults, ranging in age from 27 to 71 years, with a mean age of 42 years. All respondents self-identified as being of Aboriginal descent, including three people who self-identified as Métis. The other eight respondents self-identified as First Nations and came from a variety of backgrounds, including Cree, Ojibway, Dene, Saulteaux and some mixed origins. Five of the respondents spoke Cree or Saulteaux and, even if they did not speak it regularly at home, they noted that they were still able to communicate using the language. One respondent understood his native

languages, (i.e., Dene and Sauteaux) yet could not speak them; five of the respondents spoke only English.

Two respondents reported being born and raised in Saskatoon, whereas four others had come to Saskatoon from other Canadian cities. Five respondents were originally from nearby reserve communities and often travelled back and forth between the city and their home reserve. Three of the respondents were either originally from, or have current ties to, the same reserve community and it is unknown whether they were familiar with each other and/or perhaps volunteered for the study together. One of the respondents was adopted into a non-Aboriginal family as part of the 60's scoop (i.e., this term represents a flurry of adoptions of Aboriginal children that occurred in the 1960s, many without consent) (Reading, 2009; Sinclair, 2011) and, later in her life, returned to Saskatchewan to discover and learn about her original heritage. Regardless of birthplace or previous place of residence, respondents were residing in Saskatoon at the time of the interview.

However, many respondents reported a transient life between the city of Saskatoon and reserve communities. Some of the reasons reported for originally coming to the city were to "escape" or "get away" from "reserve life" for family, work, or educational opportunities, or that a spouse was considered an outsider and not accepted into the reserve community. Some of the reasons respondents expressed travelling back and forth to their reserve included: returning to see family members; for scheduled visits with their children who were in foster care on the reserve; or wanting to maintain close ties to their home community.

Living arrangements were highly varied. For instance, one respondent lived in a trailer, another was homeless, four of the respondents lived in a house (2 owned, 2 rented), four rented an apartment, and one respondent owned an acreage property. Two respondents lived alone, six

lived with family members (either immediate or extended), three lived with a spouse or common-law partner, and the respondent who was homeless reported frequently staying with friends. A couple of the respondents noted that transportation was not an issue and they had access to multiple vehicles; whereas the majority of respondents did not have a vehicle and traveled on foot or by public transit.

Three out of the 11 respondents had also been involved with the correctional system. One was completing a life-sentence and reported being on life parole. Another was also on parole and the third reported being in and out of the prison system for many years, but was “done with it now.”

The respondents’ level of education also varied, ranging from grade eight to a Master’s degree candidate. All respondents were literate and capable of writing in English. Similarly, the socio-economic status ranged for the respondents. Eight respondents were on social assistance whereas two had regular and steady employment; one worked in a casual position. Most respondents stated that their lives were exceptionally busy, so even if they were not formally working they were, for instance, raising children, volunteering, or actively seeking employment.

Although participation was voluntary, all respondents involved in this study were selected on the basis of several criteria: all respondents needed to self-identify as being Aboriginal and be formally diagnosed with hypertension by a qualified health care provider (see screening questions in previous section). Lastly, all respondents needed to be currently residing in Saskatoon.

Informed consent was obtained, free from coercion (see Appendix F). As well, respondents were aware of their right to withdraw at any time. Respondents were also informed that there would be a subsequent research component aimed toward action in which they had the

option to participate, if they so desired. Interview respondents were compensated with a small honorarium (\$20) as a token of gratitude for their participation.

Roles I had with respondents. I had various roles in my relationships with the respondents and communities including: being a student, a recipient open to learning about practices and values relevant to the community, facilitator, provider of technical information, interviewer, advocate, and guide. My role as an outside researcher and as a non-Aboriginal person was particularly salient. Although I did not build capacity in the deliberate manner that I had originally conceptualized for this project, the respondents frequently described how the interview (and focus group) discussions prompted them to reflect on their situations, their experience, and that this reflective process was in itself transformative.

Interviews. I conducted individual, semi-structured interviews with the 11 respondents which allowed me the opportunity to discover the respondents' beliefs, perceptions, and attitudes about hypertension and its treatment recommendations. The interviews involved discussions about issues of general health behaviours, beliefs about hypertension, adherence and attitudes toward treatment recommendations, and the quality of relationship with the respondent's primary health care provider, which in all cases was a physician (see Appendix C for the interview question guide). Each interview contained its own sequence and reflected the unique experience of the interviewee and the dynamic way our conversations catered to what was most salient for each respondent. However, all interviews covered the main topics and culminated in my asking specific action-driven questions that focused the respondents to think more broadly about hypertension in Aboriginal populations, prevention, and systemic changes that could potentially be made to improve the overall situation.

Urban Aboriginal Peoples and Hypertension

In an effort to avoid any potential assumptions about the respondents' comfort level with respect to medical institutions or the University, all interviews took place in the community at a location that the respondent selected as most preferred by him or her. Similarly, as public health reports from the city of Saskatoon have described that access issues play an integral role in health issues, I placed importance on the interviews being conducted at an accessible and convenient location for each respondent. As a result, I conducted the interviews in a variety of settings, including workplaces, coffee shops, hospital cafeterias, and the university campus.

As I began to schedule interview times and locations, I realized that I was going to need more patience during this process than I had previously thought. There were a number of respondents who did not show up for the interviews. In fact, just under half of the respondents interviewed did not show up on the first scheduled meeting.

I discovered relatively early on that some of the potential respondents were certainly interested in the study and genuinely wanted to participate, but tended to live unstable lives. Some respondents did not have a home phone and were not able to contact me to inform me that something had come up that prevented them from attending the interview. Others were single mothers who ended up having to take care of sick children. Other respondents were unable to afford a bus pass and were hesitant (or unwilling) to mention such information. When the weather dropped below -25C plus wind-chill, some did not want to walk to the designated meeting spot. Such experiences helped me to have compassion and understanding that whatever was inhibiting the respondents from making the scheduled interview also provided significant insight into how the respondents' everyday life might clash with the inflexibility in our current, structured health care system.

Although it was frustrating when respondents did not attend the scheduled interviews, I used this time to reflect on the study. For instance, I considered how this arranged meeting was ultimately my agenda, and that if I truly was there to work with the community, I needed to know that meeting on my time and schedule was not always ideal for others. I was also fortunate to have had such a promising and dedicated interest in the study from the communities and there was no shortage of available respondents. This abundance of interested respondents allowed me to relax during the unpredictable circumstances, and have faith that the research would get done when it was meant to get done.

On other occasions, respondents were late, and again, the information gleaned on such occasions was very telling, e.g., from a sore knee that inhibited someone from running to the bus, a fight with a partner, or suddenly needing to see a child and family social worker downtown for an urgent situation. Regardless of these challenges, respondents came forward. Whether it took two or three meeting attempts, individuals did eventually attend. And when they arrived, they were open and very willing to discuss the issues with me at length. I believe the interviews were mutually rewarding, as some of the respondents expressed feeling grateful for someone who was willing to listen to them without judgment. I was equally grateful for the respondents' trust and openness to divulge their thoughts, feelings, and beliefs to a complete stranger. While I had predicted that there might be resistance toward my being an outside researcher, I had not anticipated the interview recruitment to run so smoothly.

All interviews were audio-taped; the involvement of translators, though not required for any of the interviews, was available. The average duration of each interview was about one hour, with the range across interviews being from 40 to 120 minutes. All audio files were transcribed, double checked for accuracy, and subsequently given back to the respondents who also verified

their accuracy and were invited to add, alter, or remove any information. I either met with the respondents in person to complete this verification task, or mailed the transcript out to them when they expressed that they wanted more time with the transcript. Respondents were asked to sign a transcript release form (see Appendix G). Changes were minimal; two respondents each added one phrase. Specifically, respondents added words to complete portions of the transcript where the recording was inaudible. If respondents were satisfied with the transcripts, they signed a transcript release form, allowing me to proceed with analysis. Unfortunately, I was not able to locate two of the respondents to verify their transcript as both were quite transient at the time of the interview. As a consequence, I consulted with the ethics review board and adopted their suggestion of using these two transcripts in my analysis yet not presenting any direct quotations from either transcript.

Focus group. After conducting all of the interviews and analyzing the data, I gathered ideas about the subsequent community-based action project. I did so by compiling all interview information relating to suggestions for action and intervention. Then, I brought this list of ideas to my dissertation research committee. Throughout this process, I became quite overwhelmed by the number (more than 40) of suggestions, and was unsure as to which ones to pursue for the action research component of my study (see Appendix H). Fortunately, those guiding and advising my study provided insight that, in fact, selecting the “right” intervention was not my decision at all. Instead, in attempting to foster participatory engagement, it is the communities’ responsibility and role to select appropriate interventions. So, I decided to hold a focus group with the participants (both the respondents and the Aboriginal advisory group) to gather their input. The focus group was, therefore, the second method employed in this dissertation research.

Critical theoretical perspectives posit that although certain aspects of the world are measurable truths (e.g., hypertension), the way in which people understand these worldly aspects is filtered through various lenses. These lenses are influenced by social, cultural, economic, and political forces and are inherently evolving as people's understandings adapt to changing external conditions. As such, I anticipated that if I gathered the original respondents together one year later in a focus group to describe their experiences and views of hypertension, different information would arise. Notably, throughout the year, the economic climate had worsened, and health care funding and employment security had weakened.

However, the focus group was not intended to enhance reliability of the interviews; nor was it considered to be just another way to glean the same information and triangulate the data. The purpose of the focus group was, then, to engage the participants in the analysis process by bringing my interview analysis and themes back to the participants, requesting their feedback, and reviewing the accuracy, validity and cultural appropriateness of my findings. In this way, the sequence of the methods (interview then focus group) was intentionally designed to engage the participants in the research process in line with action research principles. According to best practices, culturally appropriate group activities must include:

1. "The intervention is based on cultural values of the targeted group;
2. The strategies that make up the intervention reflect the subjective culture characteristics of the members of the targeted group (i.e., their attitudes, expectancies, norms regarding a particular behavior); and
3. The components that make up the strategies reflect the behavioral preferences and expectations of the members of the group"

(Marin et al., 1994, p. 350).

Cultural sensitivity, also referred to as cultural competency or cultural safety, is defined as “a characteristic of individuals who have academic and interpersonal skills, which allow them to increase their understanding and appreciation of a group’s cultural differences and similarities” (Marin et al., 1994, p. 350). Those practicing with cultural sensitivity must:

1. “Be aware and accepting of cultural differences;
2. Have the ability for cultural self-assessment;
3. Be sensitive to the dynamics inherent when cultural interact;
4. Have the required cultural knowledge of the target group; and
5. Have developed skills that facilitate adaption to diversity

(Marin et al., 1994, p. 350).

My dissertation committee encouraged me to use a culturally appropriate model by perhaps incorporating the medicine wheel and to have a theoretical structure to the focus group. I selected the backward mapping technique which begins with the end goal (i.e., What do we need to do to reduce hypertension in Aboriginal people in Saskatoon?) and then proceeded toward concrete solutions.

I contacted the Aboriginal advisory group and explained to them that I was hoping to implement a focus group and mentioned some of the challenges that had arisen for me. Similarly, they echoed my dissertation committee’s sentiment that the communities should make the final decisions regarding interventions. They also recommended that I remain open to new suggestions rather than bringing in a list of suggested actions, as the list was derived from my interpretation of the data. Further, they educated me that a depiction of the medicine wheel was based on the assumption that respondents were interested in this model; instead, I was encouraged to draw on the medicine wheel “if it came up.” I was relieved by this advice as I had

been extremely uncomfortable with having to select for others what would be suggested on their behalf.

Following these steps, I telephoned to invite the original interview respondents back for a focus group. Unfortunately, five of the respondents' phone numbers were disconnected or they had moved away. Of the remaining six, two respondents indicated that they were not interested in participating. Another respondent said she was extremely interested, but indicated that her busy schedule prevented her from attending. Three respondents expressed a strong interest to be involved and a date was set. I also invited the Aboriginal advisory group whom I deemed to be participants in the research. In the end, two of the original interview respondents were in attendance along with two members of the Aboriginal advisory group, one designated as the note-taker.

I attempted to locate a venue that was convenient and culturally appropriate for the focus group, again knowing that health care settings might send a particular message and limit responses. Also, despite the university having proper equipment and designated focus group rooms, the location was far from the target neighbourhoods and did not seem to align with the values of community-based research. Therefore, I held the focus group in a board room at a local Aboriginal youth lodge in the community. I provided tea, coffee, and water along with healthy snacks. The focus group respondents were compensated with a small honorarium (\$20) for their participation. The focus group was 2.5 hours in duration and the entire session was audio-recorded, transcribed, and then re-checked for accuracy.

Before beginning the focus group discussion, I obtained the respondents' consent (Appendix I). I also discussed issues of confidentiality and anonymity of all respondents in attendance (see Appendixes J). Likewise, I requested that the Aboriginal advisory group

members in attendance also sign a confidentiality clause to protect all those in attendance (Appendix K). The group commenced with an Aboriginal advisory group member explaining how my study was ethically appropriate. She further stated that I was ensuring accountability to the Aboriginal communities of Saskatoon through my involvement with the Aboriginal advisory group.

During the focus group, I shared with the participants a summary of my analysis of the interviews and then asked them to respond to the question, “What do we need to do in order to reduce rates of hypertension in the Aboriginal community of Saskatoon?” Despite the low attendance at the focus group, my research advisor, the Aboriginal advisory group, and I concluded that the data produced from it were rich and helped contribute to the overall findings and to the creation of recommendations for future interventions and policies aimed at reducing rates of hypertension. In addition, conducting the focus group helped me understand that engaging in qualitative and action-based research is not linear or straightforward.

Reflective Positioning

In conducting this research, I was not able to abandon all my biases and assumptions. My interest in community-based, empowerment-focused research with Aboriginal people comes partly from the experiences I had while working and volunteering on community development projects in developing countries in Asia and Africa. My experiences working with diverse populations, including cross-culturally, with individuals with disabilities, geriatric populations, children, and sexual and gender diversity have also influenced my interest in this type of research. Therefore, I have an appreciation for minority and disadvantaged populations beyond formal academic learning. I also speak three languages (two fluently) and am strongly aware that

language is a tool that frames and affects cultural knowledge and beliefs. Thus, I remained committed to conducting dissertation research about which I felt passionate.

I grew up in Canada as a member of the dominant, white, middle-class culture of privilege. However, in my adult life I have experienced what it is like to be discriminated against for being a woman and a minority by living overseas where I was visibly different and experienced prejudice and racism toward me in those situations. I have a deep sensitivity for the “other,” despite being part of the majority culture. Such sensitivity attracts me toward this type of research.

I am drawn to settings where I can connect with others and provide care giving. Such inclinations have led me toward a career as a clinical psychologist and to conducting research with vulnerable and marginalized populations. Similarly, I gravitate toward qualitative research and, in particular, methodologies that have a grassroots, community-based, empowerment focus.

Although I have recently been diagnosed with a chronic health condition, I do not have hypertension. I can appreciate the experience of having ongoing appointments with my physician and regular monitoring and maintenance of my health. In general, I do not have the lived experience of being an Aboriginal person with hypertension.

As an outsider, I cannot claim to have an understanding of what it is like to be a member of an Aboriginal community in Canada, a sub-group of society that has an extensive and tumultuous history with the colonizers. Aboriginal people in Canada are not just cultural minorities; there is much history and emotion related to their current situation. Other minority groups in Canada are not self-governed nor do they have entitlement to land. In some ways, Aboriginal people have specific legal rights and in other ways they are much more restricted than other Canadian citizens, regardless of race, ethnicity or colour. The challenge of self-government

and having reserves designated offers compensations; however it dually binds and separates, creating a “them” and “us” paradigm. Consequently, the experience of being Aboriginal in Canada contains political, geographic, social, economic, religious/spiritual, and historic implications about which I have only an outsider’s understanding.

In conducting this research, I attempted to be open-minded and accepting of the respondents’ views toward health. Of note, I believe that a traditional Aboriginal framework toward health is a paradigm through which Aboriginal people can seek to reclaim tradition and values. It is also my intention to be appropriately critical of the biomedical model of health given the resources, power, yet poor impact of this model on the health of Aboriginal persons.

Along with my personal biases and position within society, I also had preconceived notions regarding the present research, my respondents, and Aboriginal health. I assumed that the individuals whom I interviewed might have varying ideas and beliefs related to the Western health system, their health status, and treatment methods. For instance, some might hold beliefs in line with a biomedical approach whereas others may not. As I have read the literature in this field, I have formed some preconceived notions and expectations, specifically that historical and socioeconomic forces largely shape the present state of health for Aboriginal peoples in Canada and that these forces have an impact on the views of the respondents about their present condition. Similarly, there is much evidence that racist attitudes continue to exist in health care interactions with Aboriginal patients in Canada (King et al., 2009). Consequently, I assumed that some, if not all, of the respondents have had direct experiences of discrimination.

I am also aware of a general mistrust of researchers, particularly of outside researchers, (i.e., not from the community) among Aboriginal peoples due to oppressive and unjust past research (e.g., helicopter research, stealing traditional knowledge or artifacts, etc.) (CIHR, 2007;

IPHRC, 2004; Smith, 1999). I realized early that I needed to earn the respondents' trust and respect on their terms. Doing so involved letting go of my expectations as to how the study should unfold. Having the support and backing of the Aboriginal advisory group (i.e., having the group members' names directly on the recruitment poster, and telling the respondents that they endorsed my project and felt I was acting with integrity) also seemed to assist the communities' willingness to welcome me and to form the trust required for this type of project.

To address the issues of bias, assumptions, trust, and respect, I engaged in a thorough process of self-reflexivity for the duration of my dissertation. I took memo notes, field notes, and reflected on the process of being an outside researcher conducting cross-cultural research. I also dialogued and sought guidance from many people, namely my research supervisor, dissertation committee, the Aboriginal advisory group, my research team, as well as other critical and Aboriginal health researchers. In my attempt to be as honest and transparent as possible, I reflected on questions, such as:

For whom is the study relevant and worthy? Who says so?

What knowledge will the community gain from this study?

What will I gain from conducting this research and how does that influence me?

What are some of the likely positive or negative outcomes of this study? How could the negative outcomes be eliminated?

To whom am I accountable?

Asking such questions facilitated my self-reflexivity process. I also discovered that during the writing of this dissertation, I became more aware of my biases and assumptions. I had to make deliberate efforts to examine the excerpts from different perspectives and review the material at different points to expand on my initial interpretations. It was especially helpful to

articulate my thoughts to others. In sum, my initial ideas about the study design and the predicted results shifted as the study evolved.

Ethics for Research Involving Aboriginal Peoples

Past research involving Aboriginal peoples has not always been conducted ethically. Accounts of helicopter researchers, those who have dropped in, taken knowledge or artifacts from Aboriginal communities, and subsequently left without follow-up, benefit, or credit to the communities, have tainted the notion of research for many Aboriginal peoples worldwide (Smith, 1999). Consequently, Canadian institutions supporting Aboriginal research, i.e., Canadian Institutes for Health Research (CIHR) and the Indigenous Peoples Health Research Centre (IPHRC) produced formal documents and reports outlining guidelines that health researchers must consider when they involve Aboriginal persons in research (IPHRC, 2004; CIHR, 2007). In this section, additional contributions to Aboriginal research ethics are explored in relation to this study.

OCAP principles. A major recommendation for research conducted with Aboriginal peoples is to strive to honour the OCAP principles: Ownership, Control, Access, and Possession (NAHO, 2007). Such principles form the basis of fair and ethical research. The initial principle, ownership, contends that Aboriginal communities are fully entitled to own all rights to any information being collected during research and not have sacred or traditional knowledge be unlawfully removed from their communities. Past violations of ownership include examples of pharmaceutical companies learning from Elders the healing properties of sacred medicines, unlawfully taking samples, and then subsequently patenting such newly marketed medicines (Smith, 1999). As such, it is essential that ownership is maintained collectively by the community rather than held with an individual researcher (NAHO, 2007). I struggled with this

principle as this research was part of a dissertation and it became my responsibility to analyze the data. Nevertheless, to the best of my abilities, I listened to the communities during dialogues with the Aboriginal advisory group and offered to share ownership of the project. The Aboriginal advisory group explained that they were pleased to contribute to the research, but, ultimately, they provided me with full consent to own the research.

The second principle states that Aboriginal peoples have the right to contribute to the content of research and the resulting impacts on the community. Control may be relevant to all aspects of research including from the inception of research questions all the way to the final decisions regarding dissemination. Participatory and action research methodologies foster and place strong emphasis on equal power and control (Stringer & Genat, 2004). Consequently, I found it straightforward to adhere to this principle as I sought wisdom from Aboriginal Elders, academics, key informants from the communities and organizations. In addition, during the focus group, the respondents engaged with my findings and together we strove to plan for appropriate dissemination.

The notion that respondents have a right to access information about them is the third OCAP principle. Under this principle, respondents may also make decisions about general access to related topics not included in the specific study (NAHO, 2007). I addressed this principle by providing the respondents with a copy of the interview transcript for their review and a subsequent invitation to the focus group where we discussed the ways in which my analysis aligned with the respondents' views. Moreover, the dissemination included providing an abbreviated summary of the findings to the Aboriginal advisory group, local Aboriginal newspapers and to community agencies in which the respondents had involvement.

Finally, possession is the fourth OCAP principle referring to the position that Aboriginal people have a right to possess all data and information about themselves. Separate from owning the data, research respondents are free to make choices as to where the data remain physically stored. I offered the Aboriginal advisory group full possession of the raw data, yet they encouraged me to store this information at the university campus since it was a dissertation.

I attempted to implement the OCAP principles to the best of my abilities in the present research in order to help rebuild the trust that has been broken through generations of unethical research and treatment. I strove to be accountable and was committed to conducting ethical research at all stages, including working with the communities to decide on research topic that was relevant to everyone involved, -in this case hypertension- respondent involvement with the data and analysis, and dissemination of the findings. My commitment to the OCAP principles was explicitly agreed upon in the research contract signed by the Aboriginal advisory group.

The Royal Commission on Aboriginal Peoples and the Aboriginal Action Plan.

Another key report of great significance to this dissertation is the Aboriginal Action Plan, a Government of Canada progress report written to address the Royal Commission on Aboriginal Peoples (RCAP) which highlighted progress milestones along with key areas for improvement for the status of Aboriginal peoples within Canada. For instance, the Aboriginal Action Plan identified that “health policy must assist in dispelling the legacy of poverty, powerlessness and despair in Aboriginal communities” (RCAP, 1996). Such acknowledgement of external and deep-rooted factors and the role of government provide support for this dissertation in that it aligns with critical theory, action research, and both the social and Aboriginal determinants of health (NAHO, 2007; PHAC, 2004). The Aboriginal Action plan further states that health professionals must shift from being the “expert” to becoming “partners” in improving health. By

working together with the respondents, the research is guided by the communities' rather than the researchers' priorities (Arnold & Bruce, 2005).

Recent guidelines for health research involving Aboriginal peoples note that "communities should be given the option of a participatory-research approach" (CIHR, 2007, Article 3, page 3). Following the trend in promoting culturally-competent and ethical research, the recommendations of the RCAP for improving health among Aboriginal peoples are based on four principles:

1. "Equitable access to health services and equitable outcomes in health status
2. Holistic approaches to treatment and preventive services
3. Aboriginal control over services
4. Diversity of approaches that respond to cultural priorities and community needs"

(RCAP, 1996).

Likewise, the RCAP further created the Aboriginal Action Plan which recommends that research should:

1. Pass the levers of control to Aboriginal People
2. Take a holistic approach to personal and social health
3. Provide diverse services that respond to the cultures and priorities of Aboriginal people and to the special dynamics of Aboriginal ill health
4. Bring equality in health status to Aboriginal People

(RCAP, 1996)

Such recommendations are directly in line with the OCAP principles and correspond with an action research methodology which emphasizes fairness and equality in the research process.

Action research is "democratic, participatory, empowering, and life-enhancing" (Stringer &

Genat, 2004, p. 30). Further, action research, OCAP and the RCAP recommendations promote capacity building in communities that may be hesitant to trust an external researcher (Barnsley & Ellis, 1992; CIHR, 2007; RCAP, 1996; Smith, 1999).

Data Analysis

As I selected the theoretical basis and methodological stance for this study, I realized that it was not in the best interest of the project to develop an overly complex method of data analysis as my intention was to frame the findings in ways that they could be applicable for action research. Likewise, I wanted individuals from various backgrounds to be able to review the findings and extract relevance for programming or policy; therefore, an abstract or overly theoretical approach to the analysis did not seem most appropriate. As such, I reviewed various forms of qualitative data analysis to determine the best fit for this study. I eventually selected thematic analysis as it was consistent with my goals for the project.

Thematic analysis. This study's data set comprises material gleaned from the 11 individual interviews and the focus group. To analyze this data set, I used Braun and Clarke's (2006) method of thematic analysis which is a systematic, six-phase method of analyzing a data set. The six phases consist of the following:

1. Familiarizing yourself with the data;
2. Generating initial codes;
3. Searching for themes;
4. Reviewing themes;
5. Defining and naming themes;
6. Producing the report;"

(Braun & Clarke, 2006, p. 87).

The authors state that “thematic analysis is a method for identifying, analyzing, and reporting patterns (themes) within data. It minimally organizes and describes your data set in (rich) detail” (Braun & Clarke, 2006, p. 79). Thematic analysis is widely used, yet is often employed haphazardly or at the researcher’s unguided discretion. In contrast, Braun and Clarke (2006) provide a systematic method to guide thematic analysis. As I valued having a systematic process for my analysis, this method seemed to be the most appropriate fit. Thematic analysis, in this case, is not theoretically-bound as it might be in other forms of qualitative data analysis such as interpretive phenomenological analysis (IPA). As such, this method of analysis goes well with a variety of approaches, including critical approaches as there is opportunity to analyze both the realist dimensions of overt analysis and the broader context with latent analysis (Braun & Clarke, 2006).

Although Braun and Clarke’s (2006) method of analysis is systematic and highly applicable for psychological research, it is not a formula to be followed rigidly. Rather, the phases are guidelines and, as the researcher, I found myself returning to all phases, and repeating phases that had previously been “completed.”

Transcription. Data analysis commenced with transcription of the audio interview files. Initially, I hired an outside transcriptionist who consistently worked with our research team and who was familiar with the confidentiality procedures to transcribe the initial three interviews; I completed the transcription of the other eight interviews. Both I and the hired transcriptionist strove to preserve the language in its exact form, including pauses, noises, and minimal acknowledgements. For all files – whether transcribed by myself or by the hired transcriptionist—I verified the transcripts for accuracy. Overall, my involvement in the transcription process afforded me an initial level of analysis.

After all interviews were transcribed, I uploaded my transcribed written and audio files to NVivo 8 which is qualitative data analysis software. This software allowed me to highlight and code areas of text. Further, NVivo 8 allowed me to assign multiple codes to one segment of text. One of the benefits of using data analysis software was that I could select a coded excerpt while also still having the capacity to view it, in context, within the original interview transcript. In doing so, the larger context of each excerpt was preserved. In addition, for each code, I could see all data excerpts from one respondent or I could compare data excerpts across respondents. Although I included the two unverified transcripts (see above) in my overall analysis, no excerpts from either unverified transcript are presented in this dissertation.

Phases of analysis. The initial phase of analysis involved becoming familiar with the data (Braun & Clarke, 2006). Since I had conducted all of the interviews and focus group, I was able to draw on my experience of being present during the initial phase of the research. A conference presentation that I gave based on my research (Calverley, 2009) also prompted me to become familiar with the data, which I did by reading the transcripts countless times. I documented my train of thoughts and ideas for codes prior to coding the data. Reading the interviews without a pre-determined objective or understanding in mind, I attempted to remain open to spontaneous thoughts and interpretations.

I began the second phase of analysis, coding, many months later. As I read the excerpts, I selected codes based on several different strategies. First, I highlighted and coded the overall topic of the sentence, paragraph, or whatever constituted the relevant section that was explicitly about something I thought was interesting or relevant in some way. For instance, “I take my pills from time to time” would be coded under *Adherence* and *Pills*. Often, these codes were directly related to the question posed or to information gleaned from my reading of literature on relevant

topics. At times, I was directly searching for a response to a question and would code that response specifically. For example, “Do you ever go to see a Medicine Keeper?” was coded under *Medicine keepers*.

I found that, since my initial read of the transcripts, I could identify different understandings and interpretations of the data. Therefore, taking this time away from the transcripts was necessary. I went slowly, line by line, and carefully scrutinized the data; this process facilitated my ability to see multiple meanings in the data. I then broadened my search and began including larger paragraphs as codes. I quickly began to see how the codes overlapped. At this time, I also began to document my ideas regarding potential themes and sub-themes, or the connections between codes.

Next, I created codes that were more covert, exploring a deeper, latent, or more psychological interpretation of what the data were suggesting. For instance, some codes, at this stage, were completely distinct from the question being posed. An example would be coding the phrase “I have had high blood pressure for a long time” with a latent code of *Shame* rather than something more overt, such as *Experience with having hypertension*.

I coded the data using both inductive and deductive strategies so that I could appreciate how respondents responded to specific questions, yet also to explore deep-rooted factors highlighted in critical theory that are rarely made explicit (see Appendix L for a complete listing of codes). Along with examining the respondents’ responses, I also found it enlightening to pose the question “What’s not being said here?” or “Why might this person be responding in this way?” and “How did my questions frame their responses?” Such questions prompted my engagement in meaningful reflexivity.

Phase three, turning the codes into themes, began with my writing and reviewing notes in my research journal. I attempted to group codes that related to each other into sub-themes. Some of the codes I had were essentially the same idea only with opposite valence. For instance, *Poor health behaviours* and *Healthy lifestyle choices* could be subsumed under the sub-theme: *Health behaviour*.

Next, I printed all the codes and cut them into individual slips of paper. I scrambled these codes into one giant pile on the floor and then randomly turned over a couple of them and contemplated potential relationships between the codes that had not initially been apparent to me. Then, I began to expand this process to multiple (three or four) codes at once and attempted to tell a story of how they were connected. This process was not only creative, but helped me to arrive at unexpected and rich interpretations of the data. Most ideas I derived at this stage consisted of sub-themes.

Following this process, I drew out thematic webs and trees linking intricate sub-themes. This step honed my ability to differentiate the more overarching and broader themes from the more specific and subsuming sub-themes. Several sub-themes were entirely unique and unrelated to the others. As a result, I created a theme titled *Miscellaneous*.

This process continued for several months and the themes and sub-themes became increasingly refined and sophisticated (phase four). Of course, theme refinement required a return to the initial phase of becoming familiar with the data set. I frequently revisited the transcripts to ensure that the themes I generated were indeed reflective of, and related to, the data (see Appendix M for all themes). The three phases of analysis (phases three, four, and five) directly associated with creating the themes were cyclical, particularly as I incorporated new data

(from the focus group) a year following the individual interview data. I frequently revisited the earlier phases of analysis, notably the expansion of my initial reflections from phase one.

At times, it was hard to conceptualize anything novel; so, space and time away from the analysis were always a virtue, as I could return to the data and develop new ideas. However, after approximately one year of this process, I was satisfied that I had analyzed the data sufficiently, was not generating any new ideas, and realized I had a compelling analysis upon which to base my results chapters. This point represented the conclusion of my thematic analysis for the interview data.

Subsequently, I organized the most prominent themes and then, during the focus group session, I requested feedback from the respondents on the main ideas of the analysis. Using the respondent feedback, I returned to the entire analysis and re-prioritized which themes I identified as meaningful and worthy of further analysis. Following this step, I transcribed the focus group audio, uploaded this file into NVivo 8, and began to follow the steps of thematic analysis as previously conducted. This process took approximately two months. Eventually, I combined all the data and selected the three themes that I found most compelling (phase five) which constituted the foci of my analysis: *Morality and Individual Responsibility*; *Lay versus Expert Knowledge*; and *Treatment Issues*.

The sixth and final phase of Braun and Clarke's (2006) thematic analysis involves producing the end-product-- in this case a doctoral dissertation. The main ideas and three prominent themes are explored in further depth in the form of separate chapters. All ideas converge along with a description of the dissemination of the findings (action research) in the discussion chapter.

Chapter 3: The Morality of Health: Who is Responsible for Being Healthy?

Introduction

Have you ever felt ashamed for eating too much fried food? Have you had pangs of guilt for not exercising when you promised yourself you would? Or have you felt proud of and good about yourself when you have made a deliberate effort to eat foods high in antioxidants and omega 3s and 6s? How do you feel after you go to a fitness class? Engaging in health behaviours has been shown to be related to one's level of self-efficacy and self-esteem (McAuley, Lox, & Duncan, 1993; Sonstroem, 1997). However, the pursuit of health and wellness goes beyond individual motivation or results; strong societal messaging is ripe and it communicates the societal push to be healthy. For example, Tiggemann and Williamson (2000) posited that socio-cultural pressures to be healthy and fit play a large role in why people maintain exercise regimes. They contended that exercise was related to well-being; however younger women who exercised in response to societal pressures to be thin demonstrated reduced levels of body-satisfaction. In contrast, when exercise was motivated by health-enhancement reasons, the respondents felt empowered and pleased with themselves (Tiggemann & Williamson, 2000). Such findings provide evidence that contemporary social discourses valuing health and fitness are compelling and influence individual behaviour change.

Most of us have fallen prey to societal messages that we must be healthy and devote great time and effort to maintain our health. It is easy to understand how we internalize these messages; we also apply the same values and standards in our judgments of others. For instance, if we have knowledge about the perils of smoking, consuming alcohol, eating red meat, and being sedentary, and yet we continue to engage in these behaviours, what does that say about us? What do we think about individuals with emphysema who continue to smoke cigarettes? Such

examples can evoke emotional reactions and demonstrate that our society is quick to form moral judgments about individual health behaviour. Moral assignments of behaviour are the “should” and “should not” judgments toward others. This chapter focuses on the way in which we attribute moral underpinnings to health behaviour and hold the individual responsible for his or her own health.

Concepts of blame, stigma, and power are frequently included in Aboriginal research; however, there remains a dearth of public health, health psychology, and medical sociology literature on chronic health conditions and issues of morality for Aboriginal persons. In this chapter, I describe the respondents’ experiences of shame, blame, and responsibility, along with hope, motivation, and pride toward hypertension.

Despite an overwhelming amount of research conducted with local Aboriginal communities, little is known about how Aboriginal people experience and make sense of having hypertension. Notably, Aboriginal people in this study had mixed feelings toward the Western, bio-medical health care system, yet all respondents expressed feeling guilty and powerless at times regarding their health status, as well as feeling somehow that they were individually responsible for having and treating hypertension. As the impact of social determinants, such as education and income, on health is well established, it seems short-sighted to focus health promotion activities solely on the individual (Public Health Agency of Canada [PHAC], 2003a; Raphael, 2009; World Health Organization [WHO], 2008). I am interested in investigating ways that our limited focus on individual health promotion and behaviour change is serving us and how we might envision broadening our perspective so as to become increasingly successful in reducing rates of hypertension in Aboriginal communities.

Historical Progression of Morality and Health

Prior to an exploration of the relevance of morality and health to the current study, it is germane to examine the historical progression of this currently adopted social discourse. Where does the moralizing of health originate? Throughout history, humans have assigned moral meanings to human behaviour as a means of understanding what is right and wrong (Conrad, 1994). During times of major infectious disease, such as the bubonic plague in the 14th century, which is said to have been the largest natural disaster to have ever struck the Eurasian continent, citizens needed to justify such mass mortality. As a way of fulfilling this need, deep moral judgments and racist beliefs were formed toward certain segments of the population. Despite current scientific understanding that the plague is transmitted by fleas infecting dead rodents, in the 14th century it was believed that human transmission of the plague was possible.

Accordingly, humans were deemed responsible for plague transmission and moral judgments became an inevitable reality (Herlihy, 1999). In particular, Jewish people, previously accorded respect and equal status in European society, were blamed for the bubonic plague, as rumours circulated that they caused the “Black Death” by poisoning well water (Herlihy, 1999). Anti-Semitism took hold leading to widespread persecution and violence toward Jewish citizens at that time. In a later outbreak of the “Black Death” in the 19th century, Chinese people were blamed for bringing the plague to the shores of Australia, Hawaii, and California (Echenberg, 2002). In these examples, entire ethnic groups were blamed and held responsible for mass disease and mortality.

Historically, the moralization of health has also become associated with Protestant values prominent during the 18th century (Crawford, 2006; Townsend, 2009). Crawford (2006) argued that values of self-control, rationing, abstaining, and individualism were particularly encouraged as demonstrations of devotion to God, but were also the same values required to adhere to strict

health regimens such as restricting one's diet or exercising. Consequently, these values became the cornerstone for middle-class society and the bourgeoisie, values which gained further prominence in the 19th century, and still exist today (Crawford, 2006; Townsend, 2009).

Since the 1970s there has been a new explosion in society's focus on health that places even greater emphasis on the individual to become better educated and self-informed about his or her health (Crawford, 2006). This focus was a shift away from the collective responsibility and socialist models for health that were espoused in the 1960s (Crawford, 2006). According to Crawford (2006), this change led to a greater sense of individual agency and to a greater onus on the individual to alter one's health behaviour. From 1975-1985, health became redefined, not only in sociocultural discourse, but also in policy. This shift parallels the advent of the sub-discipline of health psychology and its prolific entry into the medical world, which, along with medicine, selected the individual as the primary agent of change (Stam, 2004).

Two pivotal documents highlighting this shift were the Lalonde report (1974) and the Ottawa Charter for Health Promotion (WHO, 1986). The former report delineates the limitations of the traditional (individualistic) approach toward health by highlighting broader influences on health which Lalonde termed the health field concept, including the environment, lifestyle, and biological factors, rather than simply factors related to the health care organization (Lalonde, 1974). Lalonde's groundbreaking report was an essential factor in the development of the social determinants of health and in the push toward encouraging individuals to modify their lifestyles to enhance health. As the primary focus at that time centered on the role of health care organizations, Lalonde proposed a health promotion strategy which shifted greater responsibility to the individual to alter his/her own health vis-à-vis lifestyle modifications. The health promotion strategy coupled with regulatory, research, health care efficiency, and goal-setting

strategies (e.g., to ensure safety of water and food quality, enhanced monitoring and research of disease in Canada, and cost-cutting measures) would ensure that all facets of health are addressed.

The Ottawa Charter for Health Promotion (WHO, 1986) was an international agreement that was created in 1986. This agreement advocated “health for all” by 2000 by enhancing methods of health promotion. The six areas outlined in the agreement requiring action consist of:

1. “Build healthy public policy
2. Create supportive environments
3. Strengthen community actions
4. Develop personal skills
5. Reorient health services
6. Moving into the future “

(WHO, 1986).

The Ottawa Charter for Health Promotion also specifies three prerequisite actions necessary for good health: advocate, enable, and mediate. In particular, good health requires the amelioration of the social determinants of health through advocacy, the enabling of conditions whereby individuals can make healthy choices, and mediation on the part of government, social, and health care institutions.

The Lalonde Model and the Ottawa Charter for Health Promotion were formative, landmark documents in the progression of health understanding in Canada and worldwide. Both documents uniquely influenced society’s contemporary understanding of health, notably the focus on individual responsibility and how health should be modified.

However, what was previously considered a helpful shift to enhance individual responsibility for one's health might now be considered an obsession. In the 21st century, many people are highly informed about all the nutrients they are ingesting per serving size, the perils of non-organic food, the muscles involved in specific types of physical exercise, and the most optimal ways to achieve health, according to the experts. Health food stores are no longer a rare commodity and most major grocers now offer an entire aisle devoted to health food and related products.

Along with such a wealth of healthy options comes the dark side of our health obsession. Beliefs that drinking water from the tap is less pure than the healthier alternative have fuelled a 22 billion dollar bottled water industry (Barlow & Clarke, 2002). This industry has now expanded, and the current trend is vitamin water--water with added ingredients and colouring to make its appearance more attractive and with an array of options to suit one's needs: rejuvenate, relax, power, focus, and so on. Culturally, we are bombarded by scientific evidence that specifies what is, and what is not, healthy, the precise biological mechanisms involved, and effects on the human body of engaging in certain behaviours. Whether the emphasis lies in the marketing of health products or in the push for science and research to uncover the latest findings, the end result is palpable: the current societal discourse is that health must be a priority for everyone (Crawford, 2006).

Individual versus Shared Responsibility for Health

In understanding the reasons why people become ill, it is logical to want an explanation for the occurrence of illness or disease. When we assign moral judgments to individuals, the onus becomes placed on individuals to change their behaviour in order to redeem themselves. As it is, the societal discourse invoking moral blaming for the aforementioned reasons caters to the

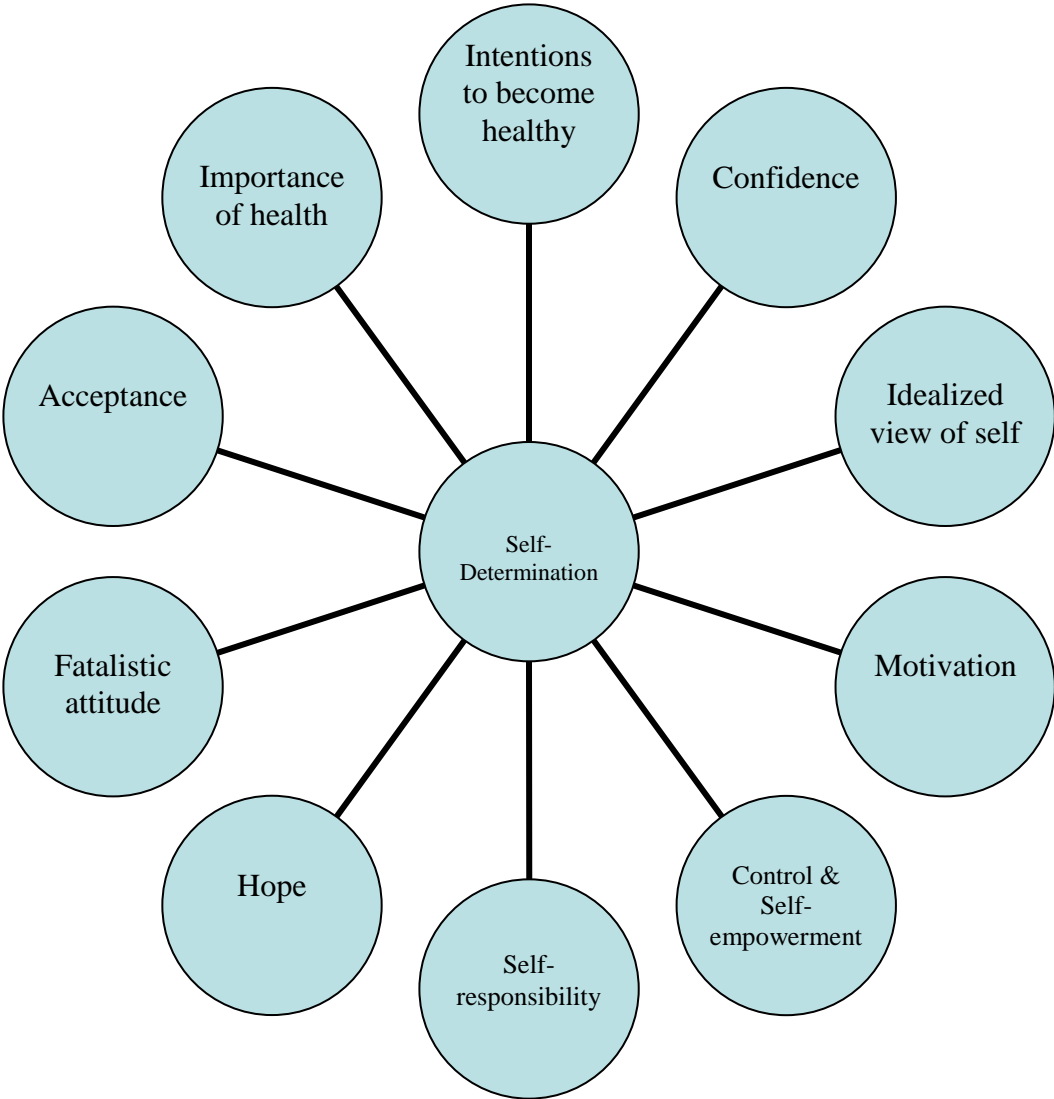
common practice of blaming the victim, in this case, the individual who is affected with hypertension. When we blame the victim, the victim is judged for being unhealthy (Conrad, 1994). Poor health is seen as shameful and a character defect. Consequently the reaction toward such individuals is to hold them responsible.

In the following section of this chapter, I demonstrate how notions of morality and health, as described in the literature, relate to the contemporarily-adopted individual responsibility discourse in this study. The respondents in the present study varied in the degree to which they took up the individual responsibility discourse; some respondents reported being proud of their successes while others felt more ashamed. Some respondents were conflicted and challenged the discourse; others described ambivalence or a mixture of reactions. Of note, all respondents described feeling a sense of responsibility for their health status and stated that having hypertension was a (direct or indirect) result of their own actions.

Data Analysis

The synthesis of my data analysis informed the overarching theme of *Morality and Individual Responsibility*. Essentially, as previously discussed, fostering a sense of individual responsibility for one's health can ultimately be empowering, yet it can also be victim-blaming. During the interviews and focus group, the respondents explored both the benefits and challenges of taking up the individual responsibility discourse for health and the following figures illustrate the various manifestations of that discourse. Using a particular method of thematic analysis (Braun & Clarke, 2006), I generated an overarching theme, which I called *Morality and Individual Responsibility*, that was created by the culmination of intersecting codes. Also, I generated two sub-themes: *Self-Determination* and *Lack of Agency* that are juxtaposed to form

Figure 2. Analytic Codes of Sub-Theme: Self-Determination.



the larger theme. Stemming from the first sub-theme, *Self-Determination*, Figure 2 displays the codes used to form the analysis of this sub-theme.

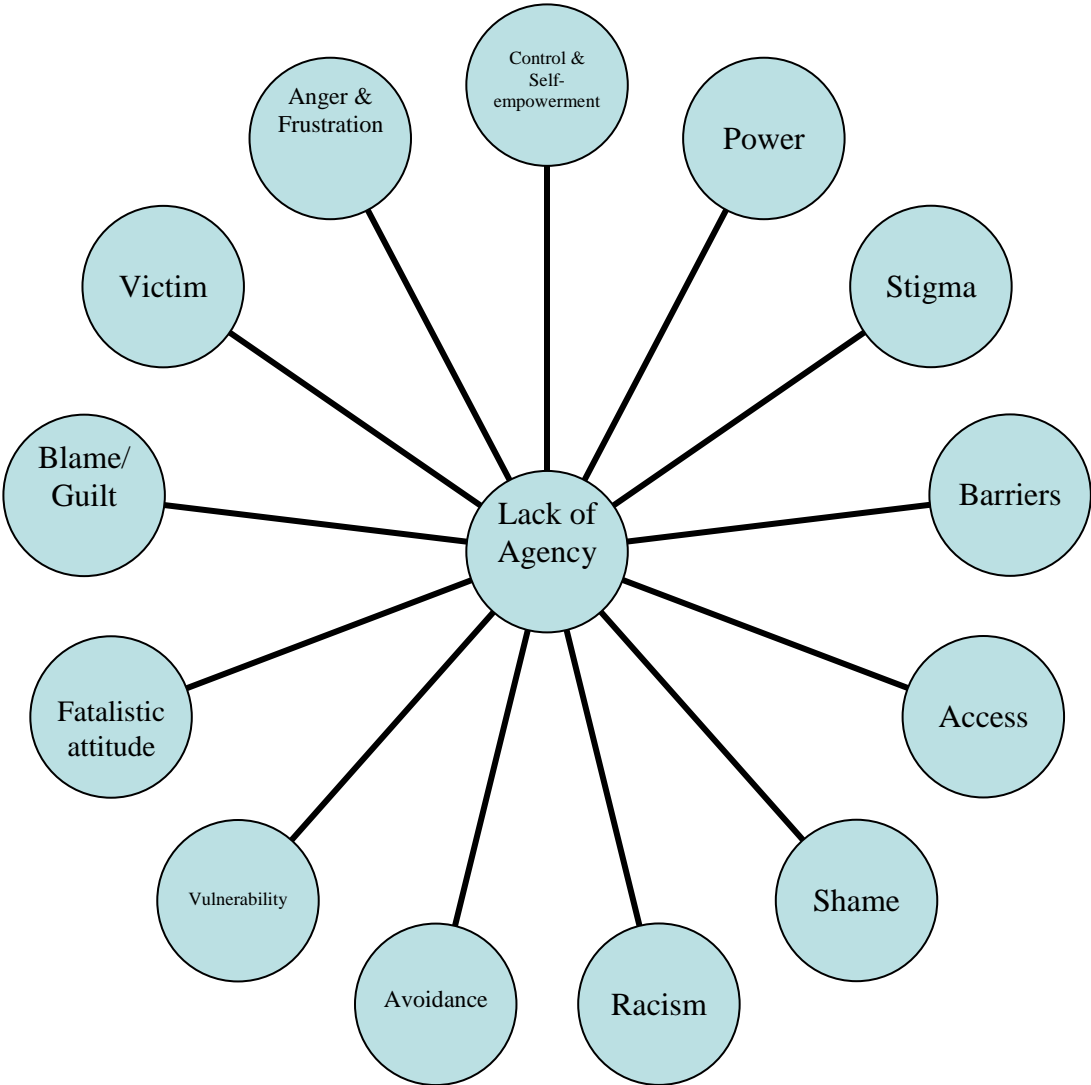
Altogether, ten codes were combined to create the sub-theme of *Self-determination* which captures the experience of personal agency, power, and control over one's health. Additionally, other codes describe experiences in which respondents were realistic about being imperfect; however they expressed hope, motivation, and intention to improve their health.

Figure 3 represents the 13 codes in the analysis of the second sub-theme *Lack of Agency*, in the overarching theme *Morality and Individual Responsibility*.

Agency, in this case, refers to feeling a sense of control or ownership of one's life. A lack of agency refers to feeling powerless and a victim of one's circumstances. Of the 13 codes that I used to create the *Lack of Agency* sub-theme, many directly contributed to taking away one's sense of control, such as *Power*, *Stigma*, *Racism*, *Access*, and *Barriers*, while other codes were sequelae of lacking agency. For instance, *Anger*, *Avoidance*, *Co-dependency*, and *Fatalistic attitude* contributed to the respondents' powerlessness. In addition, the codes that contribute to and are a consequence of lack of agency overlap. In an effort to avoid redundancy, some of the codes will not be elaborated upon.

Some of the codes are part of each separate tree diagram, as I included interview excerpts of positive and negative valence in each of them. For instance, the codes *Control* and *Self-empowerment* are included under both sub-themes. For the *Lack of Agency* sub-theme, the *Control* and *Self-empowerment* codes reflect excerpts in which the respondent expressed feeling powerless and un-empowered; whereas the *Control* and *Self-empowerment* codes within the *Self-Determination* sub-theme include excerpts in which respondents experienced successes and felt confident about their abilities to manage and modify their health. Some of the codes, including

Figure 3. Analytic Codes of Sub-Theme: Lack of Agency.



Racism, Barriers, Access, Power, and Stigma will be addressed more in depth in subsequent chapters.

Self-determination. In the following excerpts, I provide evidence of the positive codes under the Self-Determination sub-theme and demonstrate how the codes relate to current social discourse. As popular discourse suggests, health itself is deemed an entity, unaffected by outside forces, determined by will, determination, and character alone. This discourse informs the logic surrounding moral reasoning and judgment. For instance, if we put in a good effort toward enhancing our health, we will live long, healthy, and productive lives, and will be deemed dutiful, responsible and moral citizens.

This position, i.e., that health is a result of beneficial individual changes, was adopted by some of the respondents in various ways. Respondents described feeling motivated to change their own health, and reported very positive experiences of feeling healthy and empowered as a result. One of the respondents, Colin⁷, exemplifies the notion of taking responsibility for creating change for one's health:

It's always been this slow gradual climb, when you look at the charts, like if you're 25 [my blood pressure's] always been just kind of bumping on that border all the way up there. But, and I've always known, my dad has high blood pressure too. So even when I was like 25 years old one day I decided to stop eating salt. And I did. I just stopped eating salt so there's no salt in my diet anywhere, any added salt.

In this excerpt, Colin describes how he took initiative from a young age to target what he has "always known" to be his inevitable health fate, the pending diagnosis of hypertension based on his paternal family history of having hypertension. Colin responds that with a mix of self-

⁷ For the purpose of protecting the confidentiality and anonymity of the respondents, all individuals who participated are referred to by pseudonyms.

determination and awareness of his fate, he “decided” to make lasting changes. He states, “And I did” which suggests that he was successful in his resolve to make healthy changes, in this case, to cut out all added sodium. The ease with which he describes giving up salt at age 25 suggests that this behaviour change required minimal effort, that it was made easy by his determination and resolve to do what was necessary in order to be healthy.

In the next excerpt, Alex speaks about the importance of health in his life.

Eventually, I just wanna live....like when I walked up here I just seen all these people you know jogging and guys my age you know looking damn good. I’m jealous, envious, and I wanna achieve that. I wanna be healthy and I wanna be able to live to my grandparents’ age. I just wanna live healthy and enjoy life cause I think life is really short and we’re very vulnerable as people as humans. I mean, uhhh it’s it just seems like I’m on the edge of change. Like today is you know a day of change, like walking here I never would’ve done that. I knew it was healthy for me. I knew I had to do it and it felt great.

This excerpt captures the positive sentiment of feeling successful about being healthy. Alex is saying that life is too short to be unhealthy. His words encompass many of the codes used in the Self-Determination sub-theme in Figure 2. For instance, he describes not only the importance of his health, but his recent intention to be healthy and his hope and motivation to achieve this intention. When he stated: “I knew it was healthy for me. I knew I had to do it and it felt great,” he recognized that taking one step, walking to the interview, allowed him to feel much more empowerment and control over his health.

In the following excerpt, Alex was asked what he felt was needed in order for his situation to improve.

Ahhh, I trust doctors and I know it's also, like a big part of it is my responsibility and I just have to get motivated and take the initiative and start. I'll do what I have to do you know for my health and to stay alive. That's not a problem waking up every morning and taking pills, it's just I feel I could be healthier. I don't need [pills] if there's something I can do to change it, like quitting drinking, quitting smoking, you know the diet, and more exercise. And those are the four key factors for me. Stress too like, you know it's living from cheque to cheque, it's not enough. Yeah, I have confidence though in the future and in my goals, simple as they are, it's just, right now, like looking for a job doesn't stress me out at all, like I know I could find one tomorrow if I really wanted but I'm taking this time, I'm also taking this time and taking advantage of this time to get healthy.

Alex describes how he exerts control over his health which results in actions that generate positive outcomes. He acknowledges that he is responsible for making those changes as he describes needing to "take the initiative and start." He reports a strong sense of agency and control over his situation. By not simply wanting to "wake up every morning and taking pills," he indicates how he would prefer to be motivated to make changes in the four key factors. I strongly get the sense that he believes in himself and is hopeful for his future. His words capture the notion that he chooses to be healthy, just as he chooses when to look for a job; in essence, he seems to believe that he has full control over his health. I can also see the way in which he prioritizes his health as he is presently postponing finding employment in order to take "advantage of this time to get healthy."

Catherine, another respondent, further elaborated on the position that treating hypertension lies within the patient's realm of responsibility:

Interviewer: And, what do you think of this whole idea of high blood pressure?

Catherine: Well, you could probably get over [hypertension] if you start eating right, thinking right and...(trails off)

Catherine states that altering her dietary choices and subsequently changing her attitude would allow her to “get over” hypertension. Yet, she responds in the second person. Doing so allows her to distance herself from what she is saying, as though her advice applies to other people. I am uncertain whether she adopts this attitude of embracing individual responsibility for herself. Later on she states:

Interviewer: What about your diabetes? How do you control that?

Catherine: I can overpower diabetes by “do it.”

At this point, I assume that she also believes that taking control of her own health is her responsibility. Her strategy is based on motivation for action and her response is no longer passive or tentative. She exemplifies the sub-theme, *Self-determination*, as she makes no hesitation or excuses about what needs to get done; she seems to grasp that her health is in her control and she is responsible for making those changes.

Subsequently, Catherine says:

Yeah. I have got, well I have more confidence in myself than anybody. So if somebody can show me that this will work, then I’ll do it. And if [my doctor] can show me that this will work then we’ll do it.

Catherine initially demonstrates her sense of ownership, control and ability to empower herself by having more “confidence” in herself than in others. She indicated that the only person she could trust was herself and ultimately her health was the one area where she was able to exert control. However, despite being empowered, she then reports that she is willing to be convinced by evidence provided by others--in this case her physician--to actually make change. She

switches her wording from “I” to “we,” which also parallels her shifting to becoming more open to the advice from her physician. For instance, she describes “I’ll do it” and subsequently “we’ll do it.” Altogether, Catherine comes across as somewhat conflicted about her responsibility to become healthy and moves between various positions of being in control to being less autonomous and more reliant on her physician to assist her with that goal.

Another respondent, Ben, helps to clarify how health is all about one’s mental state. His responses depict the notion that health is entirely related to the strength of his mind and that, by thinking in the right way, he could overcome anything; nevertheless, there is tension between the various perspectives that he holds.

Ben: I think, the most important thing is the mind...the mind is very powerful. People think you have to go to a doctor all the time. It’s not the doctor that heals you, it’s your mind. When you work with it, you can heal yourself. You know, cancer, all these, all these things that we have today, we created our own sicknesses you know. I don’t know what created my high blood pressure.

Interviewer: What do you think?

Ben: I really don’t know yet ‘cause I never really thought of it. But I’ve thought of other things. But, if I probably would really meditate and concentrate on it, I wouldn’t have high blood pressure. But I’m lazy. Lazy to look after my health. I abuse my...I’m a self-abuser.

Ben reports with certainty that the mind is the responsible agent for healing human suffering. At the same time, he is unclear as to what “created [his] high blood pressure.” Contrary to his earlier statements, he does not attribute his own circumstance of having high

blood pressure to his own mental “creation.” However, after explaining that he has never really pondered this question before, he asserts that if he were to “meditate and concentrate” on his high blood pressure, it could be resolved. Yet, he concludes that such focus and effort have not occurred because he is “lazy” and a “self-abuser.” Such a statement implies that being healthy requires ambition, focus, and great effort.

However, Ben highlights an interesting predicament -- ambivalence. His initial comments convey strength, agency, and responsibility; yet the final sentence contradicts his theory that all one needs is a strong mind to be healthy. Even though his willingness to be responsible for his health allows him the freedom to change when he desires to do so (through mental concentration), he is also faced with feeling like a failure when he has not succeeded in overcoming hypertension. This contradiction highlights the disconnection between Ben knowing how he could rid himself of hypertension, and not behaving consistently with this knowledge. Initially, it seems as though Ben is relating to the previous respondents in that he notes that personal strength and determination are all that are required to be healthy. Yet, by acknowledging that he has been too lazy and self-abusing to resolve his hypertension, he admits to being weak and lacking in determination.

Likewise, in the following excerpt, Alex describes a similar mental battle.

Interviewer: Well what is it about [taking pills] do you think that you don't like?

Alex: Uhh. Just being sick I guess. I don't - I don't agree with it. Yeah.

Interviewer: It sounds like you would prefer to have a bit more control over the situation, like if you take a pill already you feel more helpless than if you could change your diet or things like that?

Urban Aboriginal Peoples and Hypertension

Alex: Yeah, I think - yeah. Exactly. If I could change my diet - I'd eat so much - when I hit the gym. Work out. Then, you know. I'd be healthy. {pause} I heard - like I used to play basketball too, lots eh. I haven't played basketball in about - a year and a half or two years. So I'm going to start playing ball again and...

Interviewer: Oh, good. Sounds like you know what to do.

Alex: Yeah. I do, just - I don't know, I guess I'm a procrastinator. Waste a lot of time.

Alex also describes the tension between having good intentions to get healthy and having clarity as to how to achieve this goal (play basketball and eat healthy), while being a “procrastinator” and lacking motivation to carry out those changes. His description of becoming healthy is conditional, following an “if.....then” paradigm. He states, “If I could change my diet...work out....then I'd be healthy.” For him, health is dependent on his motivation and ability to achieve specific changes with his diet and exercise regimen. He puts a lot of pressure on himself, but seems to feel clear on what his priorities need to be in order to be his version of healthy.

All the aforementioned respondents take up the discourse that valiant effort and sheer will are sufficient for lasting change and, consequently, are a reasonable means of tackling a chronic disease like hypertension. These respondents, with the exception of Colin, all describe knowing what changes need to be made, yet they identify that knowledge alone does not necessarily translate into behaviour change. Such realities are not unique to these respondents; rather this disconnection between knowledge and behaviour represents common barriers to behaviour change.

Some of the respondents described their intention to be healthy in a more passive manner or as hope for the future rather than direct, present behavioural targets to be modified.

Nonetheless, in these circumstances, the respondents still report positivity, empowerment and agency toward their health, regardless of actual changes being made.

As evident by the respondents' perspectives, there are clear advantages of an individual responsibility for health. Respondents reported feeling empowered and experiencing self-determination and control when they were provided with options for controlling their blood pressure. Physicians, nurses, or community health care workers provide options and it is ultimately up to the patient to decide whether to follow such recommendations. For instance, a patient might be encouraged to quit smoking, reduce salt, increase daily activity levels, follow Canada's Food Guide, reduce alcohol consumption, and reduce stress. Having been educated regarding these recommendations, a patient might attempt to make all, some, or none of the lifestyle modifications. The respondents described that even when they did not engage in all the suggested treatment recommendations and lifestyle changes, they still found value and pride in every attempt they took.

As the moralizing discourse suggests that being healthy means we choose to be strong-willed, conversely this discourse also suggests that being unhealthy is interpreted as a choice. The consequences of this latter choice, however, imply that we are weak-willed and deliberately reject society's moral value to be healthy. This alternative perspective was captured in the other sub-theme, *Lack of Agency*. In contrast to feeling proud of their successes toward improving their health, the respondents also expressed feeling weak and ashamed during those times where their intentions to be healthy did not align with their actual behaviours. The previous excerpts also

contained hints of this vascillation, as frequently the respondents wrestled between feeling self-determined in some ways and lacking agency in others.

Lack of agency. Although the respondents experienced positive reactions to feeling responsible for their health, the following excerpts elucidate how the respondents internalized the responsibility for their health which resulted in negative emotional consequences. The respondents expressed feeling ashamed, guilty, angry, frustrated, stressed, or like a failure. Townsend (2009) contended that the emotional sequelae of these negative feelings can further exacerbate disease-inducing behaviours such as over-eating, eating unhealthy foods, and lack of exercise, thereby leading to greater health problems. Indeed, the respondents in this study reported engaging in such behaviours, which is unlikely to be unique to this study or an “Aboriginal” problem.

In the following excerpt, Justin illustrates the ongoing struggle for health that most of us engage in regularly:

Interviewer: Is there anything else you do when you sense those sort of [blood pressure] episodes coming on?

Justin: {pause} Worry. {chuckles} Worry about it, like I can feel it and I worry, like I worry about what that means and - it's what a weird thing. 'Cause like - it's like I need to do something but I feel like I'm too lazy to do anything. I mean, if that makes sense. I do so much in everywhere else, I really do try to get behind what I believe and I really want to make changes and differences but I can't even do that in my own life, like that's kind of strange. 'Cause it's when, like it's happening - oh. What does that mean? I mean, I really have to do something; I really have to do

Urban Aboriginal Peoples and Hypertension

something, that's great, right. Do something. And I just can't get past that, I can't get past the idea that I need to do something. To get into a point where I do something {pause} Most of it's my fault. {chuckles} You know, I think about it it's my fault. It's what I've done, like I'm not overly active. I used to, when I first moved to Saskatoon like I think a lot of bachelors it was Kraft Dinner and Pizza Pocket diet, and Hamburger Helper. That was our diet. It was cheap. I didn't make a lot of money. I paid my rent and I had about two hundred dollars a month afterwards. So it was a poor diet and a lot of McDonald's, like I do not eat fast food very often at all. I can't stand it. And that's the foodie thing coming out in me. I love good food. Yeah, like it's my fault. I eat better now but I didn't do anything. You know, like you can't just do one thing. And I KNOW that. But it's so hard. You know, I get up, sure I can go for a jog. But I have work to do. Like I REALLY have work to do. It's frustrating.

Similar to Ben and Alex's previous excerpts, Justin elucidates the discrepancy between intention to change one's behaviour and actual behaviour change. For example, the intention is evident when he says, "I need to do something," and yet he contrasts that statement by describing a lack of behaviour change by saying "I feel like I'm too lazy to do anything." Throughout this excerpt there is a sense of Justin feeling shame for not making the changes he desires and feeling like a failure. As a result, he feels compelled to make changes and take action. The motivation here is slightly different, however, than that of Ben and George; Justin wants to take action to relieve the sense of shame and guilt, rather than seeking positive consequences of being in control of his health. He rationalizes, if he were not so busy, he would have greater choices to

live the life he aspires to live. He proceeds to explain how he is a “foodie,” or someone who loves good food, and yet due to financial constraints of moving to the city and being a student, he struggles with access and resorts to eating fast food despite his comments “I do not eat fast food very often at all. I can’t stand it.” The relation between people living in poverty and greater difficulty accessing and affording healthy food is well supported in the literature (Kirkpatrick & Tarasuk, 2003). Justin also describes making small gains, yet always having the sense that his gains are never enough. For instance, he states, “I eat better now,” but then elaborates by explaining, “you can’t just do one thing” which leads to my inferring that he seems overwhelmed by the amount of change required to be “healthy.” Further, Justin expresses his frustration at “having work to do” and how, despite wanting to become healthier, his priorities remain focused on employment and making money in order to survive. Justin takes the position that achieving health seems unreasonable in the face of other major life stressors, like low income or having a lot of “work to do.”

Another respondent, Celeste, comments on how her physician is attempting to be helpful by providing treatment recommendations and yet it is her own neglect of the recommendations that maintain her poorer health. Here, she describes the challenges inherent in changing her behaviour.

Interviewer: What causes [your high blood pressure]?

Celeste: Me I think it’s the food and the stuff I drink. I never used to use a lot of sugar in my coffee, but now it’s seems like I find myself using more sugar, more cream. Like I do eat like, I still eat a lot of junk food and greasy food so I think that’s my main problem. My doctor’s trying to get me to like eat healthier. Well I’m trying to eat healthier, but it’s not that easy.

Interviewer: It's hard isn't it? So how's your doctor doing that?

Celeste: Well he put me on a special diet, to try eating like vegetables, fruits, more yogurts, more exercise. But soon as I come home like if I go somewhere, as soon as I'm home, all I do is go straight to the couch and lay down and watch TV. As soon as I get home, I feel like I'm really exhausted, from walking around so much. But I used to be really active before though, when I was younger I was like in school into all those sports things, at home I always exercised all the time. But then after, I think after I had my third girl, I just really let myself go after awhile, gained all that weight and what not.

Celeste describes similar themes as those previously mentioned; nonetheless, what stands out for me is that she believes the doctor has invested a great deal of effort in “trying” to get her to “eat healthier,” and her inability to follow the prescribed set of health behaviours is her fault. Her self-blame becomes evident in the final sentence, when she states “I just really let myself go after awhile” which points to the data analysis codes guilt, shame, and feeling like a failure for not maintaining her health. The position Celeste holds communicates vulnerability, shame, and helplessness rather than a sense of control over her choices, empowerment, and determination. Further, she displays an internal negotiation between wanting to adhere to a prescribed set of behaviours as directed by her physician (e.g., “My doctor's trying to get me to like eat healthier”), a sense of pride of past motivation and self-determination (e.g., “But I used to be really active before though, when I was younger I was like in school into all those sports things, at home I always exercised all the time”), and lack of agency (e.g., “I just really let myself go after awhile, gained all that weight and what not”). Although she speaks proudly of what she

used to accomplish, there is also shame that is implied in this sentence, shame for no longer engaging in such activities.

In the next excerpt, the respondent, Catherine, internalizes the victim-blaming discourse and denies her sense of personal agency.

Interviewer: If you could give any advice to your doctor about how to treat you best, to give you the best possible care the best treatment, what would you say to your doctor?

Catherine: Lock me up

Interviewer: Lock you up?

Catherine: Lock me up till I get better.

Interviewer: Stop you from yourself? (Catherine: nods)

Catherine attempts to make light of the fact that she does not trust herself with her health and lifestyle choices. This excerpt is in sharp contrast to the first excerpt in this chapter where Colin reports having complete trust and faith in his abilities to make the changes needed to be healthy. Here, Catherine refers to being “locked up” which evokes images of her being too dangerous and reckless to make her own rational choices. Her comments also fall under the common victim-blaming discourse, as she takes full responsibility for her health. She does not respond to any suggestion for her doctor to do anything differently, but rather, maintains that she herself is the problem and is ultimately to blame for her predicament. Specifically, she is too out of control to be responsible; others need to take charge. In a previous excerpt, Catherine occupied the position that she understood how to “get over” hypertension, as exemplified by her references to motivation and determination. She reported having a sense of control and agency when she stated “Yeah. I have got, well I have more confidence in myself than anybody.”

However, in this later excerpt, she occupies another position, i.e., one in which she needs to have others protect her from myself, take charge of her life, and take away her agency.

In the next excerpt, Justin captures the notion of powerlessness:

Justin: But I mean, I see it as - it's really just hard to believe that I have high blood pressure.

Interviewer: How come?

Justin: Well, it just - 'cause for the longest time it's associated with age. And it's not associated with lifestyle. So it was a really big shock. And it's a huge change because it's lifestyle. Lifestyle's not easy to change. It's like diet; people always talk about diets, right. Big fat, oh, you need to do this kind of diet. Do you understand what diet means? Diet is what you eat. It has nothing to do with a specific formula in that you need to do a rice diet or - you need to eat well because this is your diet. That's what diet is. So it's kind of along the same lines as that, like this is my lifestyle. This is how I've lived my life for years and now I'm paying the consequences which I mean, I should really, but it's difficult. Like, it's just a huge change. And it's - well you know, how do you see hypertension fitting into all that. Like, I just - it gives me headaches, it makes me feel really crappy some days you know, and it's me. And I know it's me but I can't - it's really hard to find that motivation

Justin expresses how he feels like a victim of poor information. His descriptions are supported by the literature: previously it was understood that, in older age, people begin to see the onset of diseases like hypertension; however, now, the onset of diabetes and cardiovascular

risk factors (including hypertension) is increasingly seen in younger people, notably in Indigenous peoples worldwide (Alberti et al., 2004). Justin is in his late 20s and, as a result, he seems to feel angry that he did not have prior awareness of this trend in order to prevent himself from getting hypertension. However, then he proceeds by saying that “Lifestyle’s not easy to change” and “I should really, but it’s difficult. Like, it’s just a huge change” which I interpret as his feeling powerless about his health. He occupies the position of blaming doctors, media, or society for not having the correct information about hypertension. Moreover, he then shifts to blaming himself when he says, “This is how I’ve lived my life for years and now I’m paying the consequences” as if he has no control or agency to execute those changes. He concludes by noting that he struggles to “find that motivation” and, ultimately, he avoids committing to making the changes as they are difficult and daunting.

Similarly, in the next excerpt, Justin humorously addresses the challenges of altering his behaviour for the sake of his health. “Quit smoking?! It’s like I KNOW, but it’s like have you ever been addicted to heroin, you know what I mean?” Justin dramatically says that, when his doctor encouraged him to quit smoking, it was comparable to the difficulty of quitting heroin, i.e., that it is nearly impossible to do so without some assistance. I interpret his parallel of quitting smoking to heroin addiction to mean that he feels like a victim, lacking in power and personal agency. This positioning of behaviour change as unrealistic is a challenge to health promotion, which proposes that motivation, desire, and will are all that is required to modify health behaviours.

Challenging individual responsibility. Some respondents in this study expressed sentiments that did not align with the *Self-Determination* or *Lack of Agency* sub-themes. Instead,

they challenged notions related to the individual responsibility discourse. During the focus group, Celeste noted:

I think like even when people have [hypertension] like me, like [doctors] always tell us to eat healthy and all that, but we still don't. But it's like, I'll just take some pills it'll go away but it doesn't. 'Cause I've been taking pills for I don't know, probably almost ten years now, yeah. Just to keep my blood pressure low, but I've tried to change my lifestyle a few times. I quit smoking, exercising, trying to eat right but it only works for awhile. Eventually I always have to go back to the same thing anyways so.

Her sentiments were echoed by Kim:

Yeah, sometimes you think that you're the one that did it to yourself. You know, by your poor diet or something like that, you know. That you could've done something to not get it and everything when actually, you know it doesn't, I don't even know how it happens, it just happens. And it affects a bunch of different people. Doesn't matter if you're overweight or skinny or black or white or whatever. Everybody can get it.

Both Celeste and Kim express similar ideas: they are contesting the victim-blame model and offering criticism of the status quo. Neither of these women occupies the position of feeling completely in control of making changes, nor do they feel powerless and guilty for not making changes. Instead, they are challenging the power structure embedded in the individual responsibility discourse by noting that the traditional top-down approach of doctors providing the patient with treatment recommendations is not always the most effective way to target a problem. Both respondents observe that it is not useful to blame oneself for having hypertension or to modify one's behaviour endlessly without results; instead they both reconcile that

hypertension is larger than their own experience. They feel no shame for not overcoming their disease and, as Kim appropriately highlights, “it just happens... Everybody can get it.”

Reflexivity and Interview Questions

When reflecting on my own contribution to these interviews, I realized that my question guide for this study perpetuated the individual as the main agent responsible for health. The way I phrased my questions focused and placed emphasis on self-responsibility and likely perpetuated the victim-blame model for disease. It was only in reflexively analyzing my data that I began to realize that I, too, was buying into this discourse of individual responsibility. For instance, I asked direct questions related to lifestyle modifications that perpetuated the notion of individual responsibility, e.g., “Do you smoke? Drink alcohol? Do you think you eat a balanced diet? Get regular exercise?” Such questions likely prompted the respondents to orient to individual behaviours rather than to more broad-based understandings of health. Other examples include my responses to the respondents during the interviews. For instance, when Alex was describing how he intends to play basketball again, I responded, “Oh, good. Sounds like you know what to do.” My response undoubtedly sends the message that getting exercise by playing basketball is “good” and is “what to do” when striving for better health.

At times I asked broader questions that challenged respondents to consider why hypertension was increasing or ways to reduce hypertension; overall, I found that the respondents were uncomfortable with these types of questions. For instance, I asked “What does your doctor need to know to give you the best possible care? and “What does the city of Saskatoon need to do to reduce rates of hypertension in the Aboriginal communities?” The respondents did not seem to know how to respond to such broad-based questions and they appeared much more comfortable when they could speak from their own experience.

Conclusion

The social discourse of individual responsibility of health remains prominent today and subsequently leads to the assignment of moral judgments as to whether people successfully execute their agency or negotiate self-responsibility toward health properly. Individual responsibility creates a space in which individuals are able to execute control. Moreover, individual responsibility provides very positive consequences (e.g., empowerment, motivation, and hope). Yet it also generates very negative consequences (e.g., blame, shame, guilt, powerlessness, and anger). As I observed, the respondents nicely captured how this discourse applied to their lives, whether in beneficial, empowerment-based ways, or in victimizing ways which caused them to feel a lack of power, control, and agency. Albeit rare, several respondents also challenged the effectiveness of this discourse. Nonetheless, the individualist discourse (i.e., blaming the individual) remains dominant in the respondents' responses.

Chapter 4: Lay versus Expert Knowledge

Introduction

The exchange of knowledge during health care encounters plays a pivotal role in determining the health outcome of the patient (Karnieli-Miller & Eisikovits, 2009; Suurmond & Seeleman, 2006). In the previous chapter I examined the consequences of individual responsibility for one's health status and the cultural and societal discourses that perpetuate those leanings. In the first part of this chapter, I explore the way the respondents demonstrated their knowledge within the context of health care encounters. In wondering how patients understood diagnostic and treatment recommendations related to hypertension, I wanted to represent the substantial portion of my analysis that focused specifically on how expert and lay knowledge is negotiated. Although I do not have collateral information from physicians, which is a major limitation of this project, Aboriginal people's perspectives have historically been silenced and neglected and, for this reason, are the focus and priority of this project.

Traditionally, knowledge has been understood as a binary concept, with lay and expert ways of knowing opposing each other. Lay persons are defined as those individuals relying on personal wisdom and direct experience with their bodies, symptomatology, discrete strategies, and their own personal circumstances to inform their knowledge. In contrast, experts are defined as individuals whose knowledge is accrued by specific training and where such knowledge is required to maintain employment standards (Lidskog, 2008; Prior, 2003; Wilson, Kendall & Brooks, 2007). Lay knowledge was historically considered value-based and experiential, whereas expert knowledge has been understood as factual, scientific, and technical. Similarly, lay knowledge was seen as interesting, but often misguided or even incorrect (Prior, 2003).

Although both sets of knowledge are necessary ingredients for successful health care encounters, medical expertise is often favoured and privileged over lay knowledge (Kinsella, 2002).

However, the role of lay persons within health care is changing. Expert knowledge is no longer viewed as superior and lay knowledge as inferior (Prior, 2003). Instead, social constructionist notions have been adopted in health care settings with the consequence that multiple knowledge systems are acknowledged. This is witnessed particularly with regular training for health care providers in Aboriginal cultural awareness. Biomedicine is just one knowledge framework used to understand health (Kinsella, 2002). Biomedical knowledge is equally interpreted within a particular context and is not value-free. Likewise, lay knowledge is not necessarily incorrect and lay persons are not all alike; rather there is much variability and diversity among lay persons' grasp of technical and expert knowledge (Lidskog, 2008).

With the challenging of the expertise of medical professionals, an increasing level of democracy has been introduced into science and practice (Lidskog, 2008; Prior, 2003). This democratization began in the 1970s in the UK, as witnessed by the shift in referring to patients as *consumers* of services (Hardey, 1999; Mol, 2008). Such a shift was said to provide patients with increasing choice, independence, and power (Hardey, 1999; Mol, 2008). In recent years, the inclusion of democratic principles in health care (Karnelli-Miller & Eisikovits, 2009) has expanded to include replacing traditional paternalistic, colonial models with patient-centered, shared decision-making models, which value patient choice (Bryant, Bown, Bekker, & House, 2007; Karnieli-Miller & Eisikovits, 2009). The traditional paternalistic approach posits that physicians have specialized training and make the educated decision. In contrast, the enhanced autonomy or shared decision-making model contends that both physician and patient share knowledge in the decision-making process in a respectful, mutually-beneficial manner (Charles,

Whelan, & Gafni, 1999). This latter model emphasizes the physician's training and expertise along with the patient's lay knowledge (Karnieli-Miller & Eisikovits, 2009).

Further, expert knowledge is no longer confined solely to those people within the medical profession. Whether resulting from facilitated access to information from the internet or media sources, lay people have become technically informed and savvy regarding their health. Resulting from such efforts, many lay persons evaluate the physician's suggestions as one of several options (Hardey, 1999; Mol, 2008). Science has become demystified and lay persons are able to critically evaluate scientific health information and challenge expert opinion regardless of their medical training background (Hardey, 1999). According to Kinsella (2002), lay people can indeed possess both technical knowledge (expert knowledge) and personal or local wisdom (lay knowledge). Not only can lay persons take on aspects of the expert role, but modern interpretations of critical theory suggest that the most successful means of knowledge production encompass the collaboration of lay persons with the experts (Lidskog, 2008). These notions align with participatory and action research methodologies and current trends in Aboriginal health research (Canadian Institutes of Health Research [CIHR], 2007; Herr & Anderson, 2005; Kinsella, 2002).

Terminology has also adapted to this evolution of lay knowledge. There has been a shift in the past two decades from referring to lay beliefs to speaking of lay expertise (Prior, 2003). Such language shifts have also included the creation of the term *expert patient* coined in 1990 (Prior, 2003). The UK Department of Health created the Expert Patient Programme (EPP) in 2002 to empower individuals to be in charge of their own health and, subsequently, engage in peer education (National Health Service, 2010; Wilson et al., 2007). The EPP's have produced peer-led, self-management initiatives which are cost efficient by creating less of a burden on the

health care system. However, such programs are also controversial in that they create an expectation that patients must be responsible for their health (Wilson et al., 2007). Further, Wilson et al. (2007) found that despite the EPP being a nationally funded program, physicians still have difficulty negotiating the health care encounter with patients who have equal technical and medical expertise. Clearly, there are shortcomings to this approach, and negotiating lay versus expert knowledge is complex and multi-faceted despite attempts to equalize knowledge between physicians and patients.

In the first half of this chapter, I examine the ways that respondents demonstrated their lay knowledge; in the second half of the chapter I focus on exploring the outcomes of prioritizing expert knowledge over lay knowledge. I was interested in the consequences that occur when patients do not feel heard, or when lay knowledge is not respected in medical encounters. As the critical theorist Michel Foucault described, we construct a strong relationship between knowledge and power (Foucault, 1980); this relationship was apparent in my analysis. The notion that expert knowledge is privileged and lay people need to be taught the right way, perpetuates colonial ideals of knowledge transmission. The transformation of the traditional roles of knowledge giver and receiver to collaborators alters the power imbalance (Prior, 2003).

Nonetheless, not all forms of knowledge are considered equal. Prior (2003) argued that we would be naïve in assuming that lay persons can acquire expert knowledge to the same extent as the experts who have received training in how to properly interpret technical information. She contended that lay expertise has limits and can even be erroneous (Prior 2003). What are the boundaries around knowledge acquisition and transmission within health care encounters? I explore such questions in the latter part of this chapter.

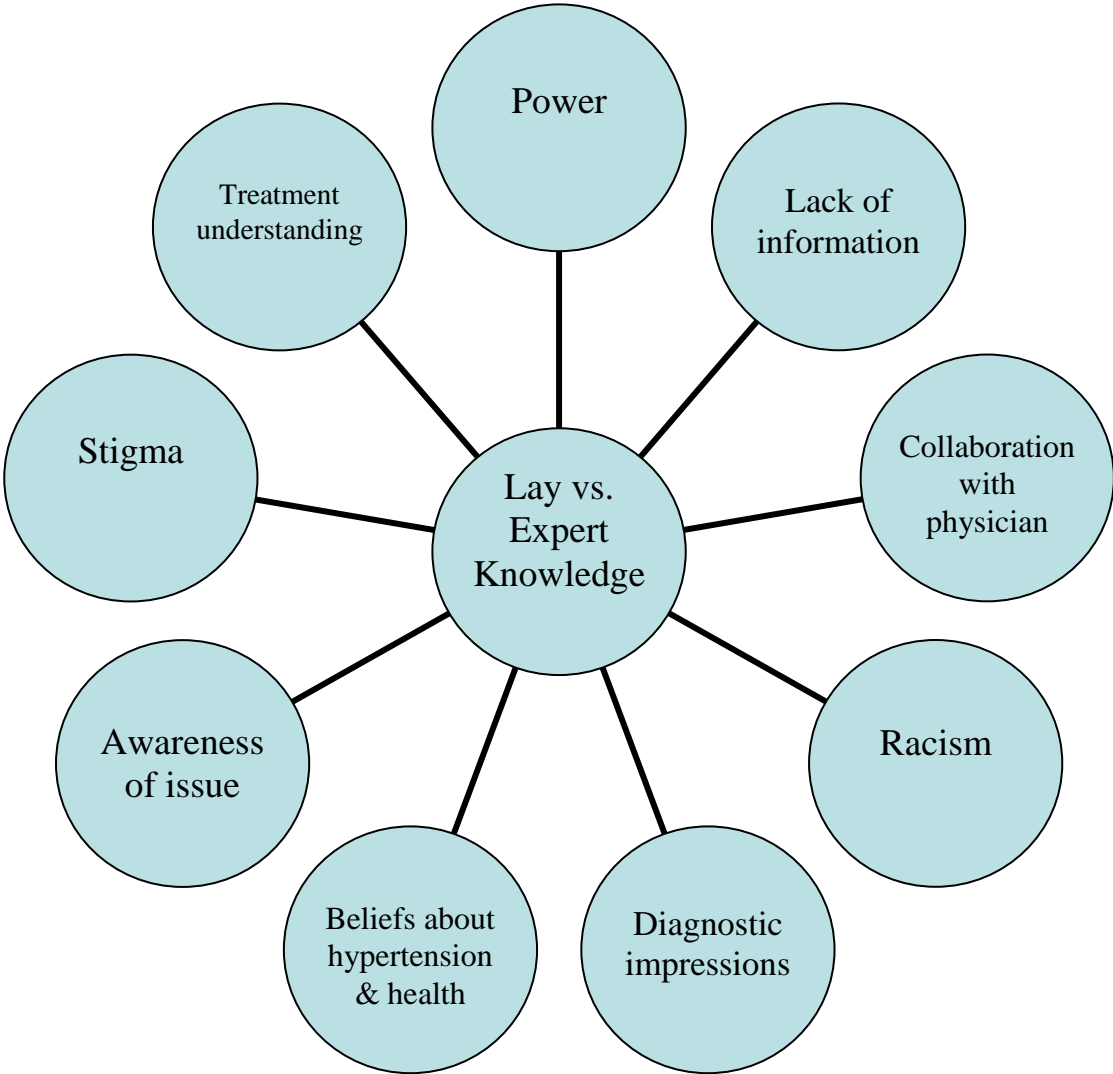
Data Analysis

Figure 4 reflects my data analysis that formed the overarching theme of *Lay versus Expert Knowledge*. During the interviews and focus group, the respondents explored both their understanding of and attitudes toward the diagnosis and treatment of hypertension and, in doing so, demonstrated how lay people hold expert knowledge.

Identical to the method of thematic analysis that I used in Chapter 3 (Braun & Clarke, 2006), I generated an overarching theme which I called *Lay versus Expert Knowledge* that was created by the synthesis of intersecting codes. Altogether, nine codes combine to create the theme *Lay versus Expert Knowledge* which captures the way that patients convey their knowledge of health. These codes were selected to inform *Lay versus Expert Knowledge* because they demonstrated the ways in which the respondents understood their personal health, hypertension, and the nuances of medical encounters. However, more than that, I was able to code the respondents' latent experiences with feeling disempowered by the expertise of the physicians. Likewise, instances in which respondents were faced with racism and stigma in medical encounters also related to how I was exploring such power differentials within health care.

Language. The following sub-section is based on information gleaned from various codes in my analysis, such as “awareness of the issue,” “lack of information,” “diagnostic impressions,” and “treatment understanding.” In understanding the medical encounters and how knowledge is conveyed, I found that the use of language was a powerful ingredient. For instance, some respondents felt that they did not describe technical expertise in the same way as their physician.

Figure 4. Lay Versus Expert Knowledge Thematic Analysis.



qualities of a disease. As she remains uncertain if diabetes and hypertension are the same disease or not, it is thus important to examine how assumptions about language in medical encounters are made. What are the consequences of diverging understandings of medical language in physician-patient encounters?

Demonstrations of lay knowledge. Lay knowledge was previously said to be different from expert knowledge, where expert knowledge has traditionally been understood as technical, scientific expertise, and lay knowledge as based on personal experience and self-knowledge (Koch, Jenkin, & Kralik, 2004). The previous excerpts demonstrated how divergent language use between physician and patient creates distance and confusion. However, other respondents spoke the same language as their physicians, and, in doing so, demonstrated their expertise with biomedicine and their increased capacity to discuss treatment options in a collaborative manner

In this excerpt, Colin confidently states what he believes to be the cause of hypertension:

Interviewer: What do you think causes blood pressure to go up?

Colin: Salt. Salt and fried foods. That's what I think and my doctor said bad diet.

Interviewer: Bad diet?

Colin: Yeah, bad diet. No veggies.

Colin takes up the biomedical explanation of hypertension, i.e., that high sodium and fat content in food are causal factors. He has found examples in his own life, his "bad diet," that support his blood pressure rising. Consequently, he and his physician are speaking the same language and sharing the same framework for knowledge.

Similarly, Ben also adopts a biomedical understanding of hypertension.

Interviewer: So, going deeper? They don't go deep, they're just looking at the top

Urban Aboriginal Peoples and Hypertension

kinda? So, if you were to give some advice or make some suggestions for doctors to help you better, what would you say, what would you say to a doctor?

Ben: I think I'd do like this doctor did. [laughs] Give me the whole thing, the blood pressure thing to find out. To really find out, and go through the whole system and probably look at the history, you know, how did you...how did you eat, how you were brought up.

Ben expresses how his physician took the time to explore his background, "the whole thing," to "really find out" all the necessary details about his family history and present lifestyle. In doing so, Ben demonstrates that patients are well aware that comprehensive history taking is essential. He recommends that physicians provide patients with the opportunity "to find out" or self-educate about hypertension. He suggests that patients gain expertise in medical knowledge to complement accurate and comprehensive patient history-taking. This stance demonstrates his alignment with the biomedical and lay expert framework of health.

In the following excerpt, Catherine and I discuss the future-oriented questions, which were posed with the intent of generating some discussion of potential action-research plans and to assess macro-level issues related to health. In this excerpt, she aptly demonstrates her lay knowledge.

Interviewer: And what would you tell other patients who also have high blood pressure if they wanted your advice, what do I need to do because I have high blood pressure, what would you say?

Catherine: I'd just say the same thing. Like what I used to do, I'd always go check like even

Urban Aboriginal Peoples and Hypertension

in the - like oh, the drug stores. They have those and I go to every drug store and I'm sitting there waiting for medication, I put my arm in there. And I would check it and that white thing and when it gets too high, that's when I go. You know, I didn't - there's, that, they do, they don't really have too much pamphlets about - yeah they do, heart - and stuff. Get physicals. Physicals and stuff like that. And ask for information. Like the information and even groups or something like that, if that could ever be and make sure they have yeah, pamphlets and you know, information out there. That's the main thing, ask for information, don't expect them to give it to you 'cause they if they're - sometimes doctors such in a rush, okay here is you're medicated now bye, I've got other patients, there's like twenty more patients and - okay but - umm. Umm. Then you say oh forget it, I'll just take it and then everything will be a happy pill, you know, that'll make it happy. {chuckles} I'll be better. But it doesn't work like that, you've gotta - you know. Get into the - deal with it like my, I only know what's problem, my - my problem is weight gain. And I've got to control that. And eat right. But I was eating all last week, Big Macs and - oh, fries, oh. I stopped.

Catherine highlights her sophisticated health expertise in various ways. She includes information about taking initiative to monitor one's own blood pressure by use of the "white thing," and that when one's blood pressure is too elevated, it is time to seek additional assistance from the physician. She is aware of the patient's responsibility to ask for information, including requesting pamphlets. She also recommends that if pamphlets cannot be provided, then a referral should be made to an agency where more information can be sought. These are all excellent suggestions that are both practical and feasible.

The following excerpt provides another example of how patients use medical knowledge about hypertension.

Alex: So. After I got that diagnosis I was like - I was just like I'm a healthy guy I think. Just I was mis - maybe mis-diagnosed. But then when I checked the, those meters at the - life store? At the Shopper's and that. Says it's high. One fifty over a hundred.

Again, Alex expresses that, even when provided with expert knowledge from his physician, he questioned this information and, instead, relied on other means to inform his notion of being "healthy." He prioritizes his knowledge over the physician's expert knowledge, until he receives other objective information from a machine which corroborates the expert knowledge. Only with the added objective evidence was he willing to accept the expert framework for his health. In line with the theory of democratization of science, patients have adopted expert biomedical knowledge, but they continue to want more knowledge and expertise (Kleinman, 1998; Lidskog, 2008). Patients, such as Alex, demonstrate their savvy resourcefulness in accessing knowledge that may previously have been considered privileged for experts only.

Similarly, in holding sophisticated understandings of expert biomedical knowledge, respondents, at times, sought more information than what was provided from their physicians, as is evident in the following excerpt:

Interviewer: In terms of what we've already discussed about the diagnosis and treatment for hypertension, is there anything you feel you would have done differently or might have been done differently by anyone involved in your experience?

Justin: Well, no, I mean hindsight's always twenty-twenty. So I mean, I wish I would have asked more questions about what it means. You know, what exactly IS hypertension. Like what is that? Why do you have blood pressure and why does it

raise? Like, I don't understand enough about physiology to really get a good understanding of what it means.... So I wish I had asked more questions about specifics. But I mean at that point I was more thinking about the immediate like what does this mean and holy cow, I have what. And it's really trying to get over that and thinking, you know, it shouldn't be too bad, I can do this and it won't take that long. That kind of thing.

Although Justin wishes he had received more specific information about hypertension from his physician, he takes responsibility and acknowledges that he wishes he could have sought the expert knowledge by asking more specific questions. He explains that he was so consumed by the meaning of the diagnosis that he was unable to think clearly about what information he hoped for at that time. As Pickersgill and Owen (1992) have noted, heightened emotions impede the decision-making process and make it difficult for patients to make quick decisions after news of a diagnosis. This excerpt speaks to the issue of timing and receptivity for patients. If patients are relying on physicians to provide them with expert knowledge, when is the most appropriate time for these conversations?

Similarly, Alex offers advice on what information a physician should provide for patients.

Interviewer: So, if you could give any suggestions or advice to your doctor perhaps to treat you better, what would you say?

Alex: What would I say? If this is like a person's first diagnosis with high blood pressure, I always say, sit down with them and get a professional and talk to them, and explain EVERYTHING thoroughly and the options, medication options. What are we gonna try, what's the next step. If it

doesn't work you know stuff like that. No offense to [my doctor], I mean it is a walk-in clinic, and in a poor part of the neighbourhood, and he sees a lot of people, but that was partly my choice to go see him just because it was so convenient and quick. But yeah, I do think it's time I see a different doctor, somebody who is experienced with high blood pressure. And giving more information and monitoring more closely

Interviewer: And specifically, what kind of information would be helpful?

Alex: Is it dropping, is it elevated, what more can I do to change it other than to quit drinking, smoking, that sort of thing.

Alex emphasizes telling the patient “EVERYTHING,” pointing to his desire to acquire expert knowledge. He emphasizes his familiarity and knowledge of health care throughout this excerpt. For instance, he demonstrates a sophisticated understanding of the format of a first session, including providing treatment options. He suggests creating a plan for treatment, which demonstrates his awareness of the shared decision-making model. In noting his disappointment with his physician he describes his preference for going to see an “experienced” physician who could provide “more information” and “monitor more closely” the progression of his hypertension. He draws attention to his knowledge of specialists and their ability to provide even more specialized, technical knowledge. Further, he understands issues related to social determinants of health and problems with health care delivery in Canada. In highlighting these broader issues, he acknowledges the dilemma of choosing between convenience and quality in health care encounters. Alex provides many recommendations that are embedded in this excerpt and he demonstrates that patients have expectations about the role of physicians, particularly with regard to sharing expertise and knowledge.

Urban Aboriginal Peoples and Hypertension

Another respondent, Celeste, expresses that she has different expectations of the way her physician provides knowledge.

Well I've found that some doctors don't really do anything. You go to them, tell them your symptoms and that, and they'll just look at you and just prescribe you pills and they really don't give you too much advice or tell you what to do. Like me, I've been going to my doctor for almost 26 or 28 years. All he does is just prescribe me pills, that's it. He doesn't really give me much advice on how to change my life [laughs].

Celeste desires more information and knowledge regarding hypertension treatment options. She suggests that her physician is withholding information and that he has the expertise she seeks but is unwilling to share it with her. As such, her expectations for the health encounter go unmet. This excerpt raises the question of domains of responsibility. What is the responsibility of physicians to share expert and technical biomedical knowledge with lay persons?

Further, it is possible that patients seek information that is not in the physician's domain of medical expertise. Lisa highlights her physician's willingness to acknowledge such limitations.

Interviewer: Okay. And what advice would you give to your doctor or doctors in general to be able to offer patients the best care for high blood pressure, what does a doctor - what needs to change or what does your doctor need to know?

Lisa: I think a lot of it is uh - I think finding out something though. I like my doctor because she just came out and said we never learned about di- di-di the diet. She said that's not my area of expertise she said you have to see a

dietitian. Some - see this lady that I'm seeing, she just said she changed her diet, she started doing a lot of juicing and stuff? And she said that's what helped her. I've - and - but I don't know what she's talking about.

Lisa describes how her physician's medical training has limitations. She appreciates that her physician is honest and appropriate with what services she is willing to offer and that she sets limits surrounding her competencies. Likewise, Lidskog (2008) contended that lay people are aware of the limitations of scientific knowledge; consequently, mistrusting expert knowledge can sometimes be appropriate. Lidskog (2008) described that lay knowledge is often more useful, specific, and relevant than expert knowledge.

Further, this excerpt raises the issue that patients may also have unreasonable expectations of their physicians to provide information that is out of their scope of practice. Is it the physician's responsibility to provide dietary advice? Boundaries of professional practice help to inform and direct patient inquiries toward appropriate referral sources. However, Lisa is seeking expert knowledge regarding diet, but is unsure as to how to proceed and obtain such information. She also describes her friend, an Aboriginal healer, about whom she gave some background information during the interview. This friend provided her with some dietary advice and stated that "juicing and stuff" was what helped her. This action might be considered another example of Lisa's seeking lay knowledge, yet Lisa remains uncertain about how to proceed. Overall, she demonstrates that it is possible to have uncertainty, and sometimes even suspicion, about both lay and expert knowledge.

Kim demonstrates how she sought a second medical opinion as a result of mistrusting the expert knowledge provided by her physician.

Well my doctor, he doesn't really say nothing, like I always have to tell him when are you gonna do my blood work again? Because I wanna get on top of this and the thing is a funny thing happened 'cause my doctor was telling me, and he wanted to, he did tests on me, and he told me that within the next six months, three to six months, that I would be on dialysis. I decided I would go to get a second opinion, there's this kidney specialist here in the hospital, because I got told about this doctor that was here that he says stuff like that but he doesn't really know that much. I actually went and got a second opinion from a specialist and they told me that I don't see why he told you had to be on dialysis within the next three to six months because your health is really good compared to the people that we do see. 'Cause he got my whole family worried about the kidney transplant and all this and dialysis... You know, so I second guess [my doctor] all the time. I go and get a second opinion all the time.

Kim illustrates that when her lay knowledge contrasts with a physician's expert opinion, she seeks out a second opinion. She expresses that her physician "doesn't really say nothing" and, consequently, she is required to assert her lay knowledge in order to get the proper care she feels she deserves, in this case, not receiving dialysis. Kim's lay knowledge does not deviate from a biomedical understanding of her health, yet she suspects that she requires a different expert opinion.

Expert patients. 'Expert patient' is a term used in the United Kingdom which refers to those individuals with a chronic condition who are educated in order to self-manage their condition (National Health Service, 2010). Although this study's respondents are not part of a formalized expert patient programme (EPP), they demonstrate the qualities of expert patients.

Specifically, the respondents are creative in how they explore and glean knowledge, and often they seek out non-traditional avenues for accessing information.

In the following excerpt, Justin demonstrates his expertise about hypertension.

I have an idea that it's like constriction in the blood vessels and blood vessels are constricted and so the heart has to pump, is pumping blood but it has to pump harder so it actually puts stress on the heart 'cause it's trying to push that blood through a smaller opening. And I mean, that may be blood vessels constricting or I'm thinking it could be build-up, plaque I guess. That sort of thing. {pause} Yeah, I know, I was asking about systolic and diastolic pressure? I don't know what that meant. But it never got explained to me as to what it is or I had to do this on the internet and through other means, the risks involved with not getting it under control. I still don't fully know but I have a good idea that it's, I mean really death is the bottom line. And that's scary. Nobody wants to. But it was more explained just like that part of it... Yeah. Like, I have these ideas of what it means but it's never been FULLY explained to me. Yeah.

Justin takes up a very technical, traditional biomedical position in his description of hypertension. However, he still expresses feeling unsettled with the amount of information that he has, despite clearly demonstrating his expert knowledge about hypertension. He did not receive the specific knowledge he sought from his physician; consequently, he had to pursue other means for accessing this information. For instance, he states that he had to go “on the internet and through other means” in order to access the knowledge he desired. In doing so, Justin demonstrates patient resourcefulness and willingness to seek out information.

The discrepancy that frequently occurs between knowledge sought by the patients and actual information provided is revealed in the next excerpt from the focus group.

Urban Aboriginal Peoples and Hypertension

Kim: Well, the thing is, I knew it was about heart, your heart and everything. The fact that you can actually have a stroke, a heart attack you know a lot of harm if it's not looked after properly. And the thing is it's like if the doctor's misdiagnosing you he could be grossly misinformed. And the thing is, I think it's not something serious, even though it is. And you're sitting there thinking, oh yeah we can deal with this with pills and exercise and diet and stuff. But end result, how do you know how much damage is already done? [Interviewer: yeah] And you know, can it really be reversed? You know can you do stuff to actually reverse it or you know stop it? Try to alleviate some of it?

Interviewer: Yeah, ummm, and Kim you have a lot of questions, right? And so, who do you think should be answering those questions for you?

Kim: Well the doctor's not. [laughs]. I've asked him so many times and he always tells me to ask the pharmacist and I ask the pharmacist and they always sit there and they're like, they'll give me somewhat, some information but I'm like, "Okay, I already know all that," you know, but they can't really sit there and tell you anything.

Interviewer: What kind of information do you get when you ask?

Kim: Hmm, lately I haven't really asked many questions, 'cause it's really no use.

Celeste: You kinda give up after awhile.

In the first part of this exchange, Kim demonstrates how she seeks a more technically sophisticated understanding of expert knowledge. She expresses valid fears about the risks of

untreated hypertension and wonders whether these risks are reversible with lifestyle modifications and medication. In elucidating her fears, she demonstrates a significant capacity for acquiring expert knowledge. However, she explores very complex issues related to science and her body that medical authorities might not be ready to respond to at the present time. Essentially, the knowledge she seeks from her physician might not be in the physician's realm of responsibility to determine the exact extent of "damage" done to her body from hypertension. When she has requested more information from her physician, she was referred to the pharmacist. Despite her attempts to be an expert patient and seek out knowledge from a pharmacist, Kim expresses that the information provided was too basic. Consequently, the gap between lay and expert knowledge widens. Although Kim claims that she seeks expert knowledge in greater depth, I find the extent of her knowledge evident. While Kim pursues a greater understanding of the risks of hypertension, she also seeks her physician's validation and respect for her bodily wisdom and knowledgeable concerns and opinions.

Allison highlights a barrier to becoming an expert patient when she says that "[the doctors] are like 'well, just go on the internet [to get more information].' Well not everybody has a computer, or, you know, ways of getting to a computer."

Allison discusses how physicians have encouraged her to become an expert patient by seeking out technical, biomedical information online. However, in doing so, an assumption is being made that patients have the necessary resources to gather their own information. Allison explains that gathering expert knowledge consisting of helpful health information requires time, money and energy. Therefore, expecting patients to become educated on technical issues might not be the best way to proceed as not all patients have access to that information. Understanding barriers to accessing expert information is a worthy area for future exploration.

Power. According to critical theory, power is an important component to consider in any analysis. I found *power* to be an especially relevant code in understanding why lay knowledge is dismissed while expert knowledge is privileged. It was not long ago when physicians were encouraged to take a patriarchal, expert role over the patient. Although the model has changed, in theory, I wondered whether the respondents experienced this power imbalance as patients. Indeed some did. This section demonstrates that expert knowledge typically trumps lay knowledge in health care encounters.

Justin expresses his desire for more expert knowledge.

Interviewer: So getting a bit more information about everything that's out there. Did you feel you got enough information about the lifestyle recommendations?

Justin: No. 'Cause I mean ... I may be different but I mean, I really want to know things. And I guess it might come down to taking things a little personally and that I'm not an idiot. And people in general aren't idiots. You can talk to them about things.

And later on in the interview, Justin discusses how physicians should treat their patients:

You need to sit down and explain to [the patient] what is going on. I mean, if anything you're going to say oh, you have hypertension and then the guy's going to be scared and think he's going to die tomorrow. You're not helping anything by just telling people, giving people terminologies and not explaining it to people. Because people aren't idiots. I mean, as much as I walk through life thinking well, that guy's an idiot - doesn't mean you're not capable of understanding something and I think part of it is making people feel comfortable and also addressing that - what's the word that I'm looking for, not dichotomist but - the gap, or the perception gap almost. Like this person sees themselves

- may not even see themselves as, but there's this perception in society that physicians are like gods. Well, I'm just a person. You know, like I'm a labourer. I don't know anything so I'm just going to take your word for it and you just take it for granted - knowledge and expertise. But it doesn't mean that people don't want to know, it almost can create like an atmosphere of fear. ...And then I went to another doctor and he was preaching in an angry way, even almost like evangelical like, you know, you're going to go to hell kind of feeling is how I felt when he was talking to me and it's like - I'm a human being. I'm an intelligent human being. You don't have to treat me this way and in fact the very fact that you are, it means that I don't ever need to see you again.

Justin initially describes his desire to gain more knowledge about lifestyle recommendations. He articulately describes the process by which patients receive a diagnosis and experience initial anxiety and fear of the unknown; in doing so, he illustrates his existing expertise and wisdom about health care encounters. In receiving information about hypertension, he expresses how he feels disrespected by the encounters with his physician and feels like "an idiot" which is in sharp contrast to his description of physicians as like "gods." He makes an important point: if a lay person does not get sufficient information about a diagnosis, "it doesn't mean people don't wanna know." He aptly claims that physicians should provide sufficient information as part of "making people feel comfortable" which, in his opinion, is a valuable component of providing a new diagnosis. Justin's eloquent description vividly captures how he felt patronized and like a victim to a powerful expert. This excerpt demonstrates how the expert approach of "preaching in an angry way" did not honour Justin's lay knowledge or his desire to obtain technical expertise regarding his health.

An excerpt from the focus group, provides another example of how a power imbalance occurs within the physician-patient encounter when there is a discrepancy between lay and expert knowledge.

Interviewer: Yeah, so you lose your power?

Celeste: Yeah, that's how I feel yeah.

Kim: Yeah, same with me. They think that just because they have a better education and everything, that they know a lot more than you do. When the thing is, it's not their body, it's your body and you know exactly how you feel. But you know, they're going by textbooks and all that, about how you feel. They just don't go by the way you feel and everything. Because they don't know how you feel.

Advisory Group member: Right, so a disconnection between like the theory and the actuality. Like they can read in a textbook and go yup, this fits. But actually, what you're saying is you have some of those things, but not all of those things 'cause there's other stuff [Kim: Yeah.] that you're describing, that you're you know talking about.

This discussion reinforces the aforementioned notion that physicians' expertise remains privileged over the respondents' personal experience. Physicians receive specialized training and therefore have specific health information; yet patients have personal experience that informs the direction of treatment. This personal wisdom of knowing "how you feel" might not be technical or measurable per se; however, without these subjective descriptions, physicians' expertise within health care encounters is incomplete. Nevertheless, the assumption persists that lay

knowledge is “misinformed” and solely based on personal experience (Lidskog, 2008; Prior, 2003; Wilson et al., 2007).

In the course of the focus group discussion, Celeste describes how such assumptions take away her credibility during health care encounters.

Celeste: Or else half the times they say, oh it’s just in your head. You think you have this or this and you think you have that symptom. ‘Cause I’ve been told that a few times. Like it’s just all in my head basically. And I tell the doctor, well if it’s all in my head, why do I feel sick, why do I feel sick? But he says there’s nothing wrong with you. Your blood pressure’s okay. You’re just going through a different stage in life. I feel like it’s not that sometimes. I feel like because he’s known me for so long, for so many years, he thinks...I dunno...[Kim: Like he knows you better than you do?] Yeah.

Interviewer: So, sometimes having the history or the long term connection and relationship with the doctor can be a bad thing? If they make, start to just assume that they know things? Is that right?

Celeste: Yeah, yeah, ‘cause like I said, I’ve been seeing my doctor for like years and years. And all he does is just look into my medical history and I try to tell him, sometimes I feel like I do have different symptoms, sometimes I feel like I’m going crazy or something. He prescribes me pills and that’s it, sends me home. I feel like they’re not doing very much at all.

Celeste comments on how she attempts to express new health concerns to her physician, but her lay knowledge is dismissed. In this regard, it is as if the physician invalidates Celeste’s self-

knowledge. She wonders whether she is “going crazy or something” since her symptoms are real despite being dismissed by the expert. It seems as though she begins to question the legitimacy of the expert authority, her physician, regardless of their longstanding relationship.

Similarly, Lisa describes her sense of feeling bullied by physicians.

Interviewer: So again in terms of everything that we've discussed, looking back is there anything you feel you would have done differently?

Lisa: [pause] Hmm. Not been so complacent I guess, you know what I mean like um I kept putting my health in other people's hands, does that make sense? Because I figured that those are the professionals. {chuckles} They knew what they were talking about or saying. But I was, I didn't realize a lot of it was trial and error. But I didn't know anything about high blood pressure too, that's the problem. Umm. Um I think - I don't know. I think if anything I would have - tried to uh - voice myself more. Yeah. And tell, just tell them like no, this is not working, find something else. You know what I mean? But - doctors have so much authority that...

Interviewer: That power?

Lisa: Yeah. That's it, it's sometimes it's hard. And then they'll smart - I don't know how they call that. They'll outsmart you or they'll - there's um some doctors that can be bullies. You don't realize it but they can be bullies, like if you try and speak up for yourself it's like who's the profess- they won't SAY it to you but they'll - it's how they respond to you. They'll go like who's the professional here, who has the education here, not you, I do. They don't realize that's how they present themselves, so you back off and

you don't say anything. And a lot of times - and that's what I, I really like about my doctor, she doesn't play those games? And it - uh I'm finding it's the people that work in the inner city doctors that work in the inner city areas, that's how they treat a lot of their patients.

Lisa blindly trusted that the experts had appropriate knowledge, but later realized that physicians' expertise is in flux and, at times, may be incomplete. The notion that biomedical knowledge is incomplete aligns with the aforementioned view that science is just one component of the knowledge required to inform health care encounters (Kinsella, 2002). Lisa describes her lack of awareness as problematic since she lacked adequate lay knowledge in order to assert herself with her physician and not be "so complacent." Yet, in wishing she had asserted her knowledge about treatment being ineffective, she demonstrates her capacity to hold the expert position. However, she observes that she withheld her expertise as "doctors have so much authority" and will "outsmart" or "bully" their patients. She mentioned that many of the physicians who work in the inner city (where patients tend to be from lower socioeconomic backgrounds) are the worst offenders of such behaviour. Lisa's excerpt highlights that even when lay people share their expertise, such knowledge can still be dismissed by physicians.

Colonialism in health care. A discussion of power between physicians and Aboriginal patients would be incomplete without addressing issues of colonialism in health care. To be clear, cross-cultural health encounters do not equate with colonial encounters; however, in Canada, less than 1% of physicians are Aboriginal (National Aboriginal Health Organization, [NAHO], 2003). This figure translates into a tremendously high likelihood that Aboriginal people are interacting with non-Aboriginal physicians and, in fact, in this study, all the respondents reported encounters with physicians of Caucasian or Asian descent. As Aboriginal

people were only very recently forced to assimilate to Canadian culture, it is logical that distrust with authority figures in institutional settings persists (Towle et al., 2006).

Our approach toward providing health services for Aboriginal people is a form of modern colonialism. Aboriginal people in Canada, who have historically been colonized and controlled by white authority figures for centuries, might find parallels in modern health care encounters between the authority figure, the colonizer (the physician), and the victim, the colonized (the patient). Medical patients hold lay knowledge that allows them to choose how to behave, what to eat, how to live; and yet patients' expertise is not valued as equal when compared to the biomedical expertise of the physicians. This situation is particularly relevant when health has become an issue in which everyone has a stake, whether for political, economic, societal, or cultural reasons. Our ideals of educating patients by providing them with expert knowledge regarding their health is, in essence, modern colonialism as it implies that lay knowledge is insufficient and requires the experts to enter and save the ignorant, under-educated patient. Saguy and Riley (2005) offered this fitting quote, "People get to discriminate against us because they're just trying to help us with our health." (2005, p. 878).

Examining these highly politicized issues is delicate as health care providers receive years of education and training and, subsequently, develop specialized expertise in biomedicine. And yet, a major component of culturally-sensitive health provision requires the practitioner to have the awareness that biomedicine is just one of many discourses that shape how we understand health. Specifically, cultural sensitivity training encompasses the understanding that there are many worldviews of health (Gustafson & Reitmanova, 2010). Despite this plethora of worldviews, the "science" of biomedicine remains prominent and privileged.

In examining contemporary colonialism, we must understand that, historically, it was immoral and shameful to be Aboriginal, to be from a “savage” group, or to marry an Aboriginal person. The church decided it was not “right” for Aboriginal parents to raise their own children; instead, children were forced to assimilate to Canadian culture by being raised in mandatory residential schools. Although the final Canadian residential school closure occurred in 1996, and there has been a shift away from forced assimilation, Aboriginal people remain caught in a confusing and complex web of policy and law (Blackstock, Trocmé, & Bennett, 2003). Further, Aboriginal peoples are now the only ethnic minority group in Canada for which race impacts their ability to access health care (Billie Littlechild, Este, Galabuzi, & Basseby Etowa, 2011). For instance, there are rarely physicians on reserve and it can be extremely challenging to arrange transportation and funding to access health services in urban centres (Billie Littlechild et al., 2011). Even though there tend to be well-trained nurses on reserve, challenges persist in accessing medical services as needed. As a result, Aboriginal status, in and of itself, has been adopted as a social determinant of health in Canada, separate from race (Raphael, 2009). While analyzing the data, I wondered whether the lay-expert relationship was viewed as colonial by Aboriginal patients, who have historically been victims of power abuses. Not only was this confirmed in my analysis, but I also discovered that the respondents felt ethnically targeted and stigmatized during health care encounters.

Justin describes his experience of feeling colonized by his physician.

And as a doctor, this is probably my own hang-up again, but physicians go through school ... I think it's seven years of school or something like that. I mean you're well steeped in this, you should be, I mean you're dealing with human lives. But it often I think sets up the relation, like a hierarchical relationship and you become, a lot of people become - what's the

word? Elitist and almost like not like in a I know more than you. Well, that's fine. But that doesn't mean that I can't understand you, right? I mean, you think you know all you want and I'll tell you right now things change. Knowledge changes constantly. So you can't really ever know anything for certain. But you need to be able to understand that a guy walks in off the street. So hey, it's an Aboriginal guy and he is from a poorer neighbourhood, he may be unemployed. He's not an idiot. That doesn't make him an idiot.

Justin articulates that, despite the extensive expertise that physicians hold, it does not give them permission to treat Aboriginal people, or patients in general, as second-class citizens. He presents the colonial hierarchical nature of the physician-patient relationship by articulating a tension between the "elitist" and the "idiot" and speaks to the likelihood of physicians feeling superior as a result of their expertise and knowledge. He appropriately conveys that lay people have expertise as he states, "that doesn't mean I can't understand you." Evidently, Justin does not feel like an equal partner or collaborator during the encounters with his physician and his lay expertise is not appropriately valued.

The idea that Aboriginal people are treated as second class citizens in health care encounters is supported by the literature (Canadian Medicine News, 2009; Hamil & Dickey, 2005; Stephens, 2009). Despite the termination of the colonization and forced assimilation of Aboriginal people in Canada, the legacy of racism and colonialism continues to be embedded within powerful structures and institutions, including health care. Likewise, racism remains ever present in health care encounters (Billie Littlechild et al., 2011; Elliot & deLeeuw, 2009; Hamil & Dickey, 2005; Stephens, 2009; Towle et al., 2006).

During the focus group, the respondents discuss ethnic profiling in health care encounters.

Advisory Group member: So, do you see your doctors in this area? Yeah? [Respondents nod] So do you think there's more stereotyping because they just look at you and go you're this and this and this. And you live here (in this neighbourhood), so you must be ... fit that profile and that's what we're talking about stigma is that they just make all these assumptions on you?

Kim: Like stereotyping you mean? [Advisory Group member: Yeah.]

Celeste: 'Cause I think they just basically just look at your files and then they see what your symptoms are all that. I think that's just basically what they go through is just your medical forms.

Interviewer: So, it sounds like you're being looked at as just the symptoms. And some information in a chart. Is that what it feels like?

Celeste: Yeah.

Kim: Yeah, well I've told my doctor yeah, well I know I have these and everything but I wanna know why I feel like this and why you know even if I'm taking the pills, why do I still feel as crappy as I do? You know and he'll sit there and he'll say "well it's cause you didn't take your pills." I'm like "I take them every day. You know but I said I still feel this way." And that's when he's like "okay. Well we'll send you for these kinds of tests and everything" you know. It's always like the haemoglobin, A1C, it's always things you know like he normally tests for when actually he should be broadening it and seeing if there's something else there instead of the same things.

This dialogue represents the sentiment expressed by many of the respondents, i.e., that their lay knowledge is dismissed by their physicians. Some of the respondents describe feeling as though it is a common experience for Aboriginal people to have physicians predicting their health issues prior to being in the actual encounter. Such labels are based on the physician's reliance on stigmatized notions of epidemiological trends in Aboriginal health rather than the specific knowledge that the patient holds. Consequently, the patient's lay wisdom and expertise is not taken seriously or respected. Kim clearly displays technical expertise and she also holds a position of having a good understanding of her subjective well-being. Despite her wisdom and knowledge, Kim feels like a lesser human being in interaction with her physician.

Likewise, Lisa describes an experience of feeling negatively judged and profiled simply by virtue of being Aboriginal.

I think that's, a whole lot of what you're talking about is holistic. No doctor is taking the whole picture from you. You know it's this constant little, like the profiling we were talking about before. They look at you and they go Aboriginal, woman, slightly overweight, you know must be diabetic, without even really getting to know your full history or symptoms that you're talking about you know like the lethargy, tiredness, lack of energy....

Lisa eloquently states the assumptions that are made about Aboriginal people. She expresses that diabetes is automatically attributed to Aboriginal people despite their presenting with other symptoms or health concerns. She also illustrates the flaws embedded in expert knowledge when physicians rely too heavily on epidemiological trends and ignore the patient's personal expertise and knowledge.

Moreover, if patients hold their own view of what is important for their health, and this view contradicts the physician's expert opinion, the patient can be labeled as noncompliant or a "bad patient." This view holds true for all patients, regardless of race or ethnicity, yet Aboriginal people are simultaneously being discriminated against for their race as mentioned above. Nevertheless, patients sometimes challenge the colonial notion that one must follow the physician's expert advice; as a result, patients feel more empowered and equal with the experts. Crossley (2002; 2003) contended that some people engage in what medical professionals deem "poor choices" as an outright form of "rebellion." Crossley (2003) claimed that the respondents in her study struggled with abiding by societal rules and expert advice on abstaining from smoking. Instead, they intentionally smoked cigarettes as a way to root themselves firmly in their lay knowledge; they expressed that indulging in some pleasures in life is what keeps them happy, and ultimately healthy (Crossley, 2003). Additionally, Crossley (2003) posited that rebelling against such suggested guidelines provided them with a sense of being more interesting, dangerous, and creative than following the status-quo.

Hence, feeling powerless in the presence of a colonial, expert authority figure (the physician) might result in rebellious actions toward expert advice. If colonialism is embedded in health care encounters, then I contend that not adhering to treatment regimes as prescribed by the colonizer can provide a sense of control or of regaining personal power. Aboriginal communities in Canada are demanding equal standing in society and are achieving it, in part, by focusing on self-determination (CIHI, 2004).

Ben describes his rebellion and seeking of independence from the health care system:

And that's the same kind of thing we have to do. All the people, it doesn't matter if we're first nations or anybody. Anybody that wants to do something about their life, they want

to start feeling good. I don't need this handout anymore; I don't have to depend on you, that's the biggest thing. I don't have to depend on this whole system the way it is today.

And later he said:

...just like high blood pressure, and what do you call it, high cholesterol, like, I have cholesterol as a matter of fact, about 6 years ago, 6 or 7 years ago, I forget, they put 3 stints in my heart, to open up some valves, but I never got them checked again (laughs). 'Cause I just, you know, if I'm gonna go I'm gonna go. You know? What can I do? If I'm gonna go, I hope I'm out in the country somewhere, so I'll feed the animals [laughter]

Ben comments that feeling disempowered by health care encounters is not a “first nations” issue, but that it applies to “anybody” affected by such power imbalances. He states it applies to “Anybody that wants to do something about their life, they want to start feeling good.” Further, Ben ridicules the emphasis placed on technical biomedical expertise as the way to maintain his health (i.e., the health consequences of untreated hypertension and high cholesterol). Rather, he remains rooted in his lay wisdom and knowledge, claiming different priorities than preventing the inevitability of death. His rebellion against the powerful expert allows him to retain control and power. He states that he does not “want to depend” on anyone else but himself, thereby embracing his independence and freedom, fostering his sense of personal empowerment and self-determination.

Conclusion

In this chapter I examined the main issues related to lay and expert knowledge. My analysis comprised an exploration of the ways that lay people hold experiential and/or technical expertise regarding their health. I was struck by the myriad ways that the respondents portrayed themselves as lacking information, and yet upon closer inspection, they demonstrated

tremendous knowledge and expertise regarding their own health. If I simply listened to the overt language, I would have primarily heard that the respondents felt disempowered by the expertise of their physician. Yet, it was important for me to look at the latent content of the excerpts to grasp the depth of understanding that respondents demonstrated regarding health. Not only did the respondents have a range of abilities to grasp technical aspects of biology, physiology, and pharmacology, they also held personal wisdom and experiential knowledge about their bodies and their symptoms. The respondents were able to decipher when the biomedical approach was working well and they could also listen to their bodies or monitor fluctuations in symptom patterns to derive relevant information.

Unfortunately, the respondents described how acquiring lay knowledge and expertise was more complex during medical encounters. The excerpts portrayed instances where several of the respondents sought, but did not obtain, more specific information from their physicians. Sometimes, the respondents' requests for information were beyond the scope of what a physician could provide, or they were referred to speak directly with other health professionals. Yet, on other occasions, the respondents felt that the physicians withheld technical information or provided overly simplified responses. Overall, the lay respondents felt dissatisfied with how their knowledge was dismissed, invalidated, or disrespected during health care encounters.

Additionally, the respondents felt that physicians held power over them resulting from the discrepancy in expertise. Despite the emphasis on the shared decision-making model within medicine, patients did not always feel equal. Such sentiment highlighted the power imbalance, racism, and stigma experienced within the health care encounter. It is frequently assumed that biomedicine is just one of many discourses surrounding health and that other ways of knowing are also appreciated and valued. However, we cannot underestimate the reliance on and

dominance of the biomedical discourse; this discourse remains preferred and prioritized over others (Hardey, 1999). Moving beyond colonialism is an ongoing project in Canada, and, in this chapter, I demonstrated some of the ongoing privilege accorded to the powerful experts in health care.

When lay and expert knowledge are fused and simultaneously respected, power is equally distributed and colonialism within health care is reduced. Aboriginal lay persons have a wealth of information and wisdom to offer health care professionals, and such knowledge is a crucial contribution to the delivery of evidence-based, ethical medicine. In order to optimize the success of health care encounters, health researchers should consider increasing self-reflection and reflexivity about the ways in which we share and disseminate knowledge. The quality of dissemination can be enhanced through research collaborations with Aboriginal lay persons. Further, as power dictates policy development, we need such lay inclusion at the policy table in order to devise programs and systems that benefit both Aboriginal persons and health care providers.

Chapter 5: Hypertension Treatment: Issues and Implications

Introduction

In this chapter I explore the layers of meaning embedded in the respondents' understanding of and orientation toward hypertension treatment. In chapter 3, I explored the responsibility for health placed on the individual for health along with subsequent moral judgment that occurs resulting from such responsibility. In chapter 4 I examined how the respondents negotiate knowledge with their physicians within the context of health care encounters. In this chapter I continue to deconstruct the political, socio-economic, historical and cultural issues related to hypertension treatment. Since I have demonstrated that lay persons hold varying amounts of expert knowledge about hypertension, in this chapter I analyze what the respondents did with such knowledge, as well as its impact on adherence to hypertension treatment.

Although the first half of this chapter focuses on adherence to antihypertensive medications for the treatment of moderate to severe hypertension, I acknowledge that best treatment practices also include lifestyle modifications. Such recommendations typically include: encouraging patients to quit smoking, reducing sodium and alcohol consumption, increasing daily activity levels, reducing stress and abdominal obesity, and following Canada's Food Guide (Canadian Hypertension Education Program [CHEP], 2011). Nevertheless, in this chapter I focus on the evocative meanings about medication use, and reveal the consequential political, social, and cultural layers of understanding. Additionally, I investigate the ways in which the dominant biomedical discourse for treatment is challenged.

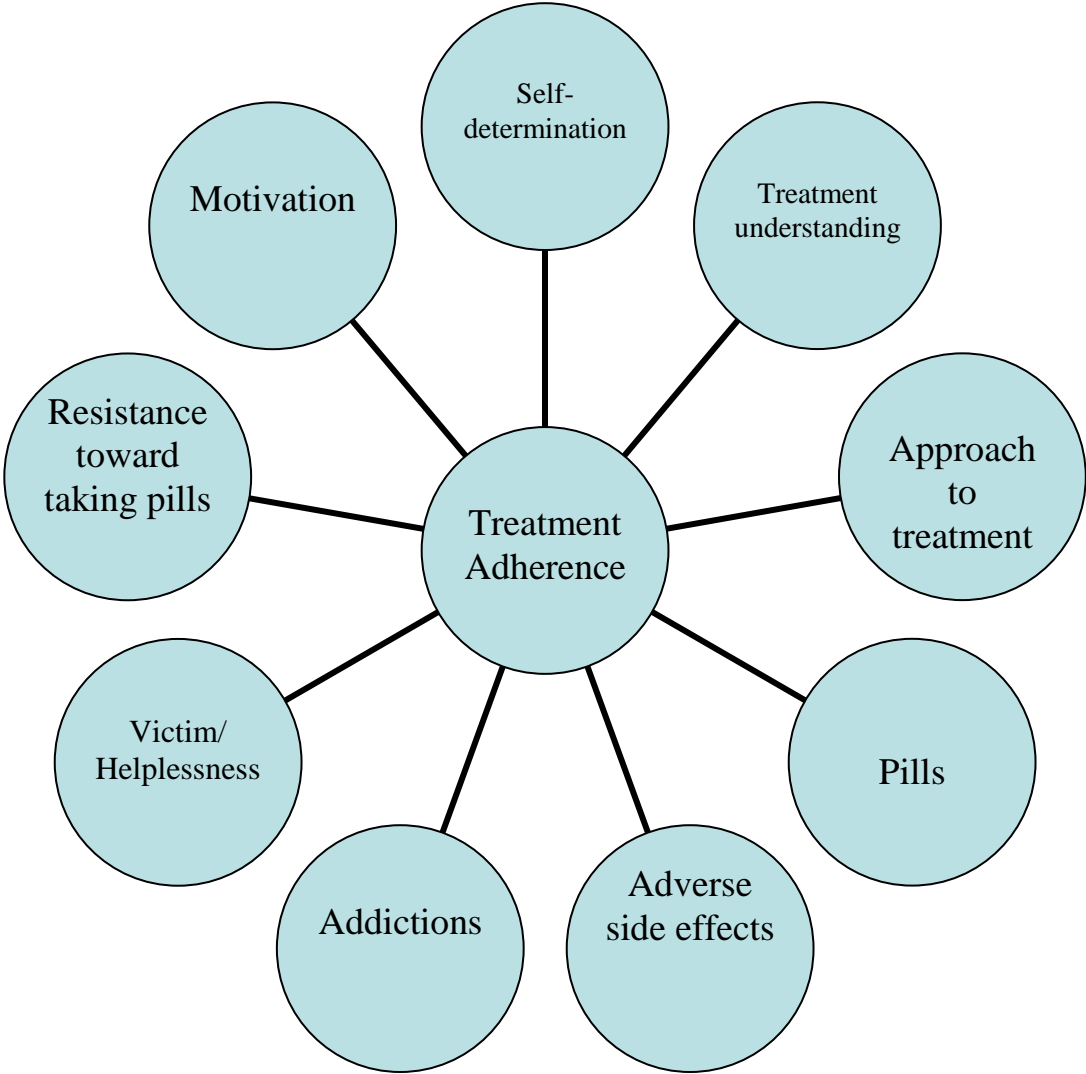
In the second half of this chapter, I consider the frameworks that the respondents employed to understand hypertension treatment. In doing so, I compare alternatives to the

biomedical framework of health, such as the Aboriginal worldview, which, in the literature, describes health as the balance between the four elements of the medicine wheel: mental, physical, spiritual, and emotional elements of being (Canadian Institute for Health Information [CIHI], 2004; Hunter, Logan, Goulet, & Barton, 2006). Accordingly, health is holistic and treatment is multi-dimensional and addresses all elements of health. As previous research has highlighted the successful integration of Aboriginal values and beliefs with dominant biomedical worldviews (Garro, 1988; Morley, 1987), I was interested in the extent to which the frameworks that the respondents employed to understand health in the context of hypertension treatment drew on these values, beliefs, and worldviews.

Data Analysis

The overarching theme of *Treatment Issues* is the combination of two sub-themes: *Treatment Adherence* and *Treatment Worldview*. During the interviews and focus group, respondents explored both the benefits and challenges of taking medication to treat hypertension. Altogether, nine codes formed the sub-theme *Treatment Adherence*, as reflected in Figure 5. These codes encompass a range of topics such as treatment understanding, approach to treatment, as well as a range of beliefs toward treatment, notably an analysis of the meaning of taking pills. In conducting my analysis, I examined each of the respondent's presentation of his/her motivation to adhere to biomedical treatment (e.g., *Self-determination*) and the subsequent results. I also explored resistance toward taking pills which overlapped with the codes *Addictions*, *Victim/Helplessness*, and *Adverse side effects*.

Figure 5. Adherence to Hypertension Treatment



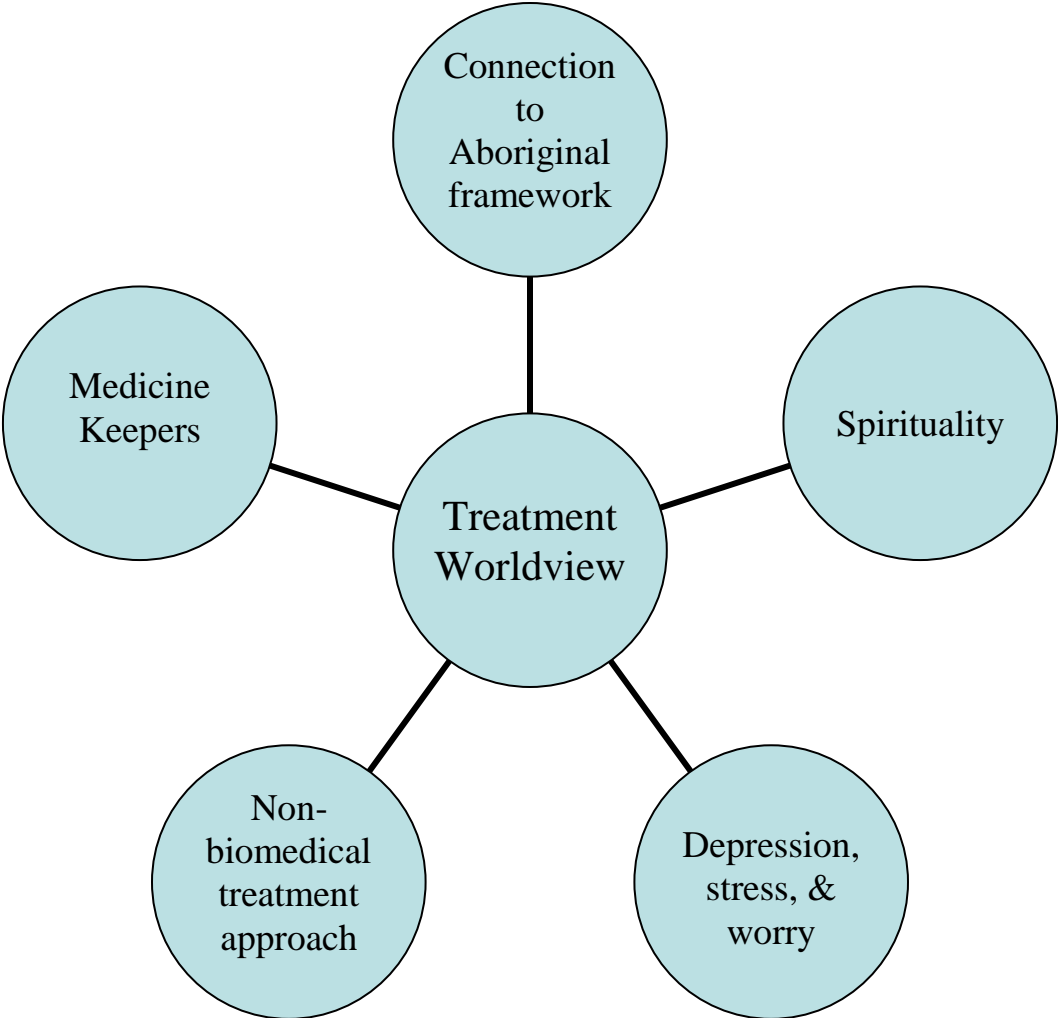
Treatment worldview was the other crucial sub-theme that allowed me to understand the respondents' approach to treatment. Five codes comprise this sub-theme which focuses on health understanding through frameworks other than the dominant biomedical framework. I examined respondents' views toward working with Elders, medicine keepers and traditional healers as represented within the code *Medicine keepers*. Similarly, I considered the various ways that the medicine wheel was adopted as represented by the codes: *Spirituality*, *Connection to Aboriginal framework*, and *Depression, stress, and worry*. Finally, another code examining other *Non-biomedical treatment approaches to health*, such as the use of Reiki, was also taken into account.

Part One: Adherence Issues

In this section, I demonstrate how the dominant biomedical paradigm of health was adopted by respondents in this study. Respondents varied in the degree to which they took up the biomedical treatment discourse. Some respondents wholeheartedly aligned with adhering to biomedical treatment recommendations; others firmly resisted taking medications; while others were ambivalent.

Medication usage is not arbitrary and meaningless; rather, taking medications is highly context-dependent and meaningful. A simple Google search or roaming through a popular bookstore highlights myriad sources which examine the controversies with medications such as Prozac, Viagra, or Ritalin (e.g., *Prozac nation* (Wurtzel, 1995); *The rise of Viagra: How the little blue pill changed sex in America* (Loe, 2006); or *Ritalin nation* (Degrandpre, 2000)). Such extensive analysis of three medications aptly captures the importance we assign to popular and commonly taken medications. We know that popular medications have evolved over time and go in and out of fashion (Cohen, McCubbin, Collin, & Perodeau, 2001; Ngoundo Mbongue, Sommet, Pathak & Montastruc, 2005). Similarly, Cohen et al. (2001) discussed how the “rational

Figure 6. Treatment Worldview.



use of medication” is a fallacy, as medications are not simply taken to relieve suffering. Instead, medications are symbolic and carry meaning. This meaning fluctuates and is influenced by the social, historical, cultural, economic, and political context.

The economic and political issues of taking medications are vast. Medications are marketed and patented for various reasons. For instance, antidepressant medications are indicated for mood disorders, anxiety disorders, sleep disorders, and chronic pain. Overall, the pharmaceutical industry is a multi-billion dollar industry; as such, this industry significantly impacts our social discourses and views of biomedicine.

However, even when there are population-based increases in medication consumption, there is simultaneously increased skepticism regarding effectiveness and safety of pharmaceutical medications (Cohen et al., 2001). Many consumers are savvy and hold strong views about taking medication. For example, despite the fact that hypertension is one of the main concerns broached with physicians many patients believe that antihypertensive medications are ineffective (Mazor, Fischer, & Billings-Gagliardi, 2008) and therefore do not adhere properly to their medications.

Alignment with treatment recommendations. In this sub-section I explore respondents’ attitudes and orientations toward medication taking and the biomedical framework for treatment. Some respondents wholeheartedly embraced the biomedical framework for hypertension treatment, as evidenced by the following excerpt.

Interviewer: And how’s it been going with taking the pills? Is that something you feel that you’re able to do regularly? [Alex: Oh yes!] Or is that hard for you?

Alex: No, I never missed a day. [Interviewer: Oh wow!] I take it with water first thing in the morning.

Urban Aboriginal Peoples and Hypertension

Interviewer: So you've never....a lot of people tend to forget to take their pills and they get too busy. That doesn't happen for you?

Alex: No, it's important enough for me that I make sure that I take it.

Similarly, Justin expresses how taking anti-hypertensive medication is absolutely necessary for his health.

Interviewer: And another time when your doctor was telling you sort of about the ways to manage or control high blood pressure, were there options given to you?

Justin: No.

Interviewer: No. It wasn't like you could take a pill OR try something else?

Justin: Well, yeah, or you can - or you could exercise and quit smoking but it needs to be gotten under 'cause it was at a point where it was REALLY dangerous she said. So like I mean, like one sixty. When she took [my blood pressure]. She said oh my God. And I was like is that bad, like I had no - like you don't know about these things. So it needed to be gotten under control at that point she said because that's such a dangerous level. And in the meantime work towards these things. Like once it's even at - not brought to normal because in order for that to happen there has to be some lifestyle changes, but just to a point where it's not dangerous, as dangerous anymore.

To ensure his safety, Justin clearly explains that it is worthwhile to take antihypertensive medication initially. He uses the word "dangerous" several times in this excerpt to highlight the risk of not taking such medication. Despite declaring the long-term merits of lifestyle changes,

he suggests that lifestyle changes would have been ineffective given that his hypertension was “dangerously” high, and unequivocally supports the use of medications for treating hypertension.

Other respondents express that hypertension medication is important to take regularly, yet they are not always so diligent in remembering to do so. Celeste is a case in point.

Interviewer: And, do you feel healthy?

Celeste: Sometimes, like sometimes, not all the time. There’s days I feel sick and days that I feel like I’m just...there’s nothing wrong with me. Depends if I take my medications or not. And then like, I feel normal, like I feel like I don’t feel sick. But then after the third day, third or second day, I start feeling like the tiredness. I start feeling like exhausted and my heart starts pumping faster. So that’s when I know I have to take [the medication]. But I can go without them like for about 2 to 3 days at the most. But I don’t do it every day, sometimes I forget about them.

Celeste illustrates that her understanding of health is modeled after the biomedical understanding. Specifically, she requires antihypertensive medication in order to feel healthy. As such, she believes that adhering to medication is important, in so far as she can remember to do so.

Episodic medication-taking for the treatment of hypertension. Hypertension is considered a chronic disease. However, the only known exploratory research with Aboriginal people living with hypertension, conducted by Garro in 1988, highlighted that the Ojibway respondents believed that hypertension was more episodic than chronic, with periods of waxing and waning. For instance, the respondents expressed that they were physiologically aware of when their blood pressure was rising (counter to the biomedical understanding of hypertension as

asymptomatic). Further, the respondents viewed treatment as necessary to remedy the acute symptoms of hypertension as opposed to the disease condition itself. A lack of observable symptoms, then, signified balance and did not warrant treatment. In this study, there were occasions during the interviews when I noticed similar types of sentiments from the respondents. Hence, the following excerpts demonstrate how the respondents continue to adopt the biomedical framework for hypertension treatment by taking medication, while also holding alternative understandings of how to take this medication, thereby supporting Garro's (1988) findings.

Ben maintains his own view of the desired frequency of medication-taking.

Interviewer: Oh ok. What makes [your blood pressure] go down low?

Ben: That's when I double these up, to 15, or if I keep on taking them every day, it's like it goes down below eh...then, I dunno, I just get d'em d'em dizzy spells. I get them.....it's like a lot of...

Interviewer: How often does that happen?

Ben: Well, I don't that's why I don't take them everyday eh, you know. So, it's better for me not to take em every day if I take em every second day. Like the last couple days, I've been taking them every day because it went kinda high and I don't want go into 15mg if I don't have to.

Ben's attitude toward treatment aligns with the biomedical understanding that taking medication is important. Nevertheless, he adds his own unique interpretation to treatment and proposes that medication can be taken on a schedule chosen by the patient (double the dosage or taken every second day). This excerpt is consistent with Garro's findings that the symptoms of hypertension are thought to be perceivable, notably via the rise of blood to certain regions of the body (Garro, 1988). In this case, Ben describes the sensation of blood going to his head causing

dizziness. This excerpt illustrates that patients' lay knowledge regarding their symptoms influences how they orient toward adhering to treatment recommendations.

The following excerpt illustrates another example of patients adhering to treatment on their own terms.

Interviewer: So how regularly would you say you take the blood pressure pills then? It sounds like there's times when you don't take them.

Catherine: [chuckles] I'm just counting how many days I didn't take them this time. [pause] my blood was all right the other - when I went there. I went oh yeah, I was coming from Extra Foods, you know the little van, those little - those truck uh, yeah, the big bus? Yeah, I went in there. One day. I went in there, I do it if there's places like that I'd stop and jump in there. And my blood pressure. It was all right they said. And that it was all right and then I'll forget to take my blood pressure pills.

Interviewer: Do you think if you hear that it's all right you're less motivated to take them then?

Catherine: Yes.

Interviewer: But if it's not all right then what?

Catherine: Then you have to make sure you take them. Yeah.

Catherine describes how she modifies her treatment regimen depending on the measurement of her blood pressure. Blood pressure fluctuates over time and we also know that patients who are diagnosed with clinical levels of hypertension are generally instructed to take antihypertensive medication daily. Catherine expresses how she "makes sure" to take her

medication when she needs it. As such, she orients toward hypertension as an acute rather than a chronic illness.

Ambivalence toward taking medications. Sometimes, respondents were undeniably allied with the biomedical notion of taking pills to treat hypertension. Other times, respondents expressed various reasons why they wished to discontinue taking medication. Despite their ambivalence, they continued to adhere to the use of medication. In the following excerpt, Kim explores the tension between these two positions.

The thing is, what worries me, I guess, I just remember seeing my kookum take, have this big, I dunno if you remember those curler liquor things that they used to have curlers in? She used to have one of those packed with pills that she had to take every day. There was about 12, about 20 pills that she had to take, different times of the day. I'm like halfway there, I have like I dunno [laughs]. There's like tons. I have like up to A through J that I have to take, E, F, G, all the way down to J. There's a bunch of them, maybe like 15 of them that I take. And the thing is like I remember growing up and everything and seeing her counting her pills and making sure she had them all, you know. Like mine's easier, it's a bubble pack. I have to take them four times a day, but what really bugs me and everything you know, is seeing her be so sick and to take so many pills, and knowing I have to take my pills for as long as she did and I'm a way lot younger than she was when she had to take hers. So, automatically, I'm like oh my god, what's going to happen to me? You know so, yeah, it's scary and I dunno. If I could change it I would. Like, I've tried losing weight, I've tried getting exercise, changing the way I eat and I haven't been taken off any of my pills yet.

According to Kim, taking medication does not lead to an improvement in one's health. Instead, she expresses a fear associated with taking so much medication at such a young age. Moreover, she equates taking medication with a decline in her health status. I have interpreted her statement, "if I could change it I would" and her explanation of attempted lifestyle changes as her desire to be off medication.

Resistance to treatment. Many people resist the notion of taking medication for a variety of reasons. For some, taking medication can be perceived as taking away one's ability to make change or as the weaker solution to one's problems. Since the diagnosis of hypertension indicates a chronic disease, pharmacological treatment is often prescribed with the knowledge that long-term medication use may be required. Some respondents disliked the notion that they had to take medication for life and wished to explore other options instead. At other times, respondents chose not to adhere to treatment recommendations because they had negative experiences. These ideas are captured by the codes: *Adverse side effects* and *Resistance to taking pills*.

The following excerpt exemplifies Lisa's difficulties with taking medication.

Interviewer: So would you say that you take your pills regularly or as prescribed?

Lisa: No. I got - I was for a long time there I think what happened was I got so discouraged? Because it wasn't doing what it's supposed to do anyway.
Yeah.

Interviewer: What do you mean by that?

Lisa: Umm. For a whole year I was on them. And they - I had a lot of side effects? And then uh - the doctor wasn't really listening. To what I was telling them. Uhh.

Interviewer: What kind of side effects were you having?

Lisa: Uh severe cramps. Yeah. Um because it had a diuretic -one of the pills I'm taking has a diuretic. Because I ended up in the hospital. I was only - 35 or something like that. Yeah. Thirty-five. And uh I had enlarged heart with an inflamed left artery. That's where the danger was, so.

Lisa explains how her bad experiences led her to feel disheartened about taking medication, whether from her experiences with negative side effects or from an episode when she was hospitalized. As a result, she no longer takes her medication.

Medication as personal weakness. Similar to studies in which the stigma of taking psychiatric medications, notably antipsychotic medications (Masad, Roca, Turner, & Kane, 2009), is examined, several of the respondents expressed that taking medications could be interpreted as a sign of personal weakness. If a patient could not fix his or her medical problems without medication, s/he had not tried hard enough. Medication becomes understood as the easy, yet superficial, fix. The counter-argument to being personally weak for taking medication is to resist medication, and thereby demonstrate personal strength. These views were captured in the code *Self-determination*.

Colin explains why he resists taking medication for hypertension.

I watched my dad live with it. And he's still alive and he's still on medication. But I watched him live with it and I learned from his experience a little bit and decided there's got to be another way. So and then I'll do whatever I can in my own way to stay off the meds. Yeah.

Colin demonstrates how patients want to improve their health without the use of medications. He exhibits self-determination in his resolve to "stay off the meds."

Likewise, Allison comments how it is difficult to associate taking medication with achieving health.

And I don't like taking pills, don't like taking anything so I'd rather do this on my own.
[Interviewer: Right.] That's why I try to think healthy, and eat healthy but I haven't been eating well.

Allison intimates that taking medication would be a sign of personal weakness. Alternatively, she prefers to make mental and nutritional changes, but acknowledges that she has been unsuccessful in doing so. Allison prefers to feel as though she has control over her health in this way.

Medication as a colonial agent. Respondents also resisted the use of medication as treatment for hypertension for other reasons. During my analysis, I came to understand that medications are both symbolic and extremely powerful. As such, medications themselves can create a feeling of disempowerment. It is as if the respondents felt that they could not control their destiny themselves and were reliant on taking medication to survive. This reliance led to several of the respondents feeling as though they were slaves to their antihypertensive medication, as if they had no options and were victims to the pharmaceutical companies. In a population that has already survived generations of colonialism and continues to experience colonialism within health care, I wondered how the ideas embedded in the code *victim/helplessness* influenced the respondents' feeling powerless toward medication.

In the following excerpt, Celeste portrays her helplessness toward frequent dosage changes.

And they tell me that if these high blood pressure, if my blood pressure goes up again, they're gonna put me on a higher dose which I don't want. I like it the way it is now, I'm

on a low dose, so, but they constantly keep changing so I feel like to me it's just one pill after another with this disease. I dunno if they're trying to help you get rid of it, or just make money out of the pills.

She queries a very important issue: Do pharmaceutical companies and their lure for potential economic gain influence physicians' treatment recommendations, specifically the decision to prescribe multiple medications and increase dosage? Celeste claims that there is no logic or proper rationale to prescribing practices as "they keep constantly changing" her dosage, which she resists. She highlights an important distinction: physicians helping their patients achieve optimum health versus physicians being accomplices to the pharmaceutical industry that has interests in gaining a broader profit margin.

Justin broaches similar political and economic issues related to the pharmaceutical industry and the medicalization of society.

Interviewer: What do you think - not just for yourself, but in general about people taking pills for high blood pressure?

Justin: I think they're pushed a lot of the times. I think that people talk about drug pushers on a playground, I don't think that some doctors and I wouldn't say all doctors, some physicians are really no different. And I think pharmaceutical companies are - definitely part of the problem in that sense that they're just, they're constantly making, like - what good is a drug and not necessarily hypertension but in general. You know, you make this drug, you put it out on the market and it's like this could help you with your arthritis. But the side effects are this, this, this, you know, and it's like I could live with arthritis or I could be completely debilitated but my

arthritis is cured. Doesn't make sense. And I think part of the problem is definitely this push that you NEED these things.

Justin likens some physicians to drug pushers. He questions the benefit of medication, particularly in the case of asymptomatic presentation of hypertension when the benefits of the medication are cancelled out by the increase in unpleasant side-effects from the medication. This excerpt sharply contrasts with Justin's earlier excerpt where he strongly justified the necessity to take his medication. This contrast denotes the ability for the respondent to have multiple viewpoints on the same topic. Likewise, tension may exist between one's understanding for the personal need for antihypertensive medication and political and societal opposition toward pharmaceutical corporations.

Addictions. One of the most compelling findings from my analysis was how respondents' experiences with drug and/or alcohol addictions combined with medication management for hypertension. Specifically, some of the respondents in this study described how their resistance to taking antihypertensive medication derived from a resistance to taking any kind of substance, a stance they formed as a consequence of an addiction history. These respondents wanted to remain "clean" or drug-free. In essence, these respondents did not see any fundamental difference between pharmaceutical 'drugs' or street drugs; both were deemed as drugs that were equally problematic. I wondered if the physicians of these patients were aware of these attitudes toward medication-taking and the related impact on treatment adherence. Cohen et al. (2001) described this exact paradox. They contrasted the overall increase in medication consumption in the USA with the "war on drugs" or national efforts to combat the illegal use of drugs. The ways in which our society values certain substances over others, for instance pharmaceutical over

street drugs, is the focus of this sub-section and reflects how meaning given to medications or drugs is influenced by social, political, economic, and cultural phenomena.

In this excerpt, Kim does not discriminate. She expresses that any kind of pill is harmful.

Interviewer: In general how would you say you feel about taking pills?

Kim: I don't like it all, I used to have a problem with pill popping. My liver problems are because of excess or taking extra Tylenol and stuff when I was younger. Means to an ends but that didn't help [laughs]. I don't know I can't stand the taste of pills I'll start gagging just from the thought of taking them.

Ben, during his interview, also equates the frequent use of over-the-counter medications such as acetaminophen or acetylsalicylic acid, with drug addiction.

Interviewer: And how do you feel your relationship is with doctors?

Ben: I really don't, I think doctors are giving too much pills. I look at doctors at sometimes they over do it. People become dependent on it. Especially people I see on the street around here. They were probably brought up on aspirin, Tylenol and everything else, so from there they become drug addicts, you know want to get that extra high. So, like people get hurt, this doctor gave me that extra pill, this is the way they can get the pill from the doctors and so it's a whole game eh. And I think a lot of them people just abuse it. You know I could make more money the kickbacks and stuff like that you know. I'm not too... I really don't trust what they do.

Not only does Ben arrive at his assumption regarding the unhealthy over-usage of over-the-counter medications, but he also describes the predicament of over-familiarity with medication. He suggests that the ease of access to medication leads to later dependence on drugs.

Similarly, Celeste describes the association between medication-taking and addiction.

Yeah sometimes, umm, I feel like I'm just getting addicted to pills all the time. It's like if you don't take them, then you don't feel okay but as soon as you take it you feel okay.

And like with her like I'm taking like about five different pills along with my blood pressure pills. So, I just feel like it's just an addiction to me, taking all these medications.

So, I don't see any way of it helping my blood pressure.

Celeste's words echo frustration that she needs medication to "feel okay" despite it feeling like an addiction to be reliant on medication in such a manner.

In the first half of this chapter, I examined treatment adherence through a biomedical lens. I demonstrated how the respondents held a biomedical understanding of treatment for hypertension, yet varied on the extent to which they adopted the discourse in their beliefs and actions. In the second half of this chapter, I shift to an examination of health through alternative frameworks, most prominently an Aboriginal understanding of health.

Part Two: Other Worldviews of Health

Based on past literature (CIHI, 2004; Hunter et al., 2006; Waldram & Layman, 1989), I made the assumption that urban Aboriginal people would likely embrace and be connected to Aboriginal healing traditions in various ways and may prefer to involve traditional healers (medicine keepers) in treating hypertension rather than a biomedical physician. Turton (1997) highlighted that Elders often provide health knowledge through practical knowledge or through spiritual methods. I explored the notion of Aboriginal worldview of health through my

questioning and, consequently, a significant portion of my analysis generated codes that supported my assumptions. I was not expecting, however, findings that contradicted previous research and my assumptions.

Medicine keepers. In exploring the extent to which the respondents took up an Aboriginal worldview of health, I wondered whether biomedical and Aboriginal worldviews could be complementary or whether respondents would align more with one particular worldview of health.

In the next excerpt, Kim considers her relationship with an Aboriginal worldview of health.

Interviewer: What do you think of Aboriginal views of health?

Kim: Honestly? I used to be all up for it and everything. My grandfather was a medicine man. They said that one of his concoctions that none of us know how to make 'cause he used to do it himself, was actually used to help cure diabetes. Some people have taken it and they've stopped having diabetic problems, and but I don't believe in that. Like I know I should, but I don't.

Kim explores her family history with traditional medicine. She states that even though she feels an obligation to seek out traditional methods of Aboriginal healing, she does not align herself with a traditional Aboriginal worldview of health. This position is most evident when she states, "I know I should, but I don't." Despite knowing that her grandfather's methods were reported to be successful at treating diabetes, Kim's conviction is firm; she does not align with the use of medicine keepers.

Likewise, Catherine describes her lack of trust of medicine keepers.

Urban Aboriginal Peoples and Hypertension

Interviewer: Have you ever gone to see like a medicine keeper for high blood pressure?

Catherine: Oh. No. {pause} No. {pause} I don't know about that when - so many people tell you about bad medicine and all those people they get really sick and I don't trust people like that. I shouldn't even be trusting with pills but the - it's you know. But you know the kind of medicine when I seen people go through they did it and someone put medicine on them.

It seems that Catherine forms her attitude toward Aboriginal worldviews based on her observations of others' negative experiences. As such, she is disinterested in pursuing healing with a medicine keeper relaying others experiences with charlatans or "bad medicine." However, she also states that she "shouldn't even be trusting with pills," thereby suggesting that she is equally cautious and restrained regarding biomedical approaches to health.

Other respondents were more mixed in their attitudes toward Aboriginal healers. For instance, Justin describes the tension that some urban Aboriginal people might face between aligning with biomedical versus Aboriginal ways of knowing.

Interviewer: How closely would you say you align yourself in general with sort of Aboriginal views of health?

Justin: {sigh; pause} I would say that I TRY to. But having been raised outside of the world view, like not really being steeped or immersed in it and I mean very colonized people. So I had to learn a lot of it, so I'm trying to re-capture that, trying to maintain a more holistic view on health. And I guess - and I would say I DON'T align myself very closely in that I don't practice. But I'm trying. 'Cause I'm starting to gain a greater understanding of what that means. And I think that that's necessary. And

Urban Aboriginal Peoples and Hypertension

if I'd been steeped or immersed in it throughout my entire life I think that it would be less work. It would be a part of your identity, a part of just your daily practices. So I'm trying. It's very difficult, I mean I think that there are some very stark differences between an Aboriginal world view and a European world view. And I've been in both, so it's kind of trying to negotiate those two. And trying to suppress one because I can see the value in the other. And end up being in a more holistic approach to health. I see the value in it.

Justin contends that it requires less effort to maintain the status-quo by continuing to align with a "European [biomedical] worldview." I speculate that he, along with some of the other respondents, is also contending with a sense of obligation toward the acknowledgment of Aboriginal ways of knowing. While he is aware of the tension between the two worldviews, he indicates that, as a result of knowing both sides, he is attempting to integrate them into a more holistic in his understanding of health.

Ben also evaluates the benefits and challenges of aligning with an Aboriginal worldview of health.

Interviewer: Do you go see medicine keepers at all?

Ben: I, see... it's very, very hard. I know some good ones, at least I know one good one so far, and I know some other people who are learning, good people who are learning, but there are a lot of people that just, they're not real, just like the preachers we hear, you know, it's like, they're the same, you know, a lot of people in Saskatoon that say well you know I'll be an

Urban Aboriginal Peoples and Hypertension

Elder here, but you know...I'll do it for the money, not because I wanna help. ...

Interviewer: So you go to sweats, and did you say you take herbal medicines sometimes? [Ben: Yeah] And is that, do you take that for your blood pressure and do you go to sweats for your blood pressure or just for you generally?

Ben: Just for me generally. Like, I go to sweats; I go there for spiritual path, you see, there's a lot of people that run sweats shouldn't be running sweats. But also when I go there, it's not him, you know, I go there, my connection is different....

Essentially, Ben claims that if a healer is “good,” then it is worthwhile to pursue healing activities. The caveat is that there are charlatans who are “not real” who are just interested in financial gain. Nevertheless, Ben states that he continues to pursue healing according to an Aboriginal worldview as part of a commitment to himself and his own healing. He reaps personal benefits from his spiritual practices rather than feeling compelled to follow the Elder or medicine keeper.

Another respondent, Lisa, took a different stance than the others. She wholeheartedly aligned with the Aboriginal worldview of health and spoke fondly about her experiences.

Interviewer: And let me just see. How would you describe yourself in terms of your Aboriginal heritage?

Lisa: Hmm. I don't know, just - I follow my culture, I follow our uh teachings.

Interviewer: Have you ever been to see a medicine keeper?

Urban Aboriginal Peoples and Hypertension

Lisa: Yeah. Ummm. One of them actually brought my high blood pressure down if you can believe it. {chuckles} Two of them uh but they're not from this area. Yeah. And uh the funny thing is they said umm this one he's from Mexico. And I saw him at - incon- uh is it the incon, no, not incon. Umm just down south of here? And uh - they had a had a - a healers' gathering there.

Later in the conversation, I asked:

Interviewer: So this person, so how did – he...what helped your blood pressure go down?

Lisa: Umm he gave me a tea. A, a bark? I have it at home, I haven't - I only was it - I only took a few - uh I think I - uh he did uh - he said one gallon of distilled water and it had to be distilled water. Yeah. And he showed me how to make the tea and I drank all of that. And uh what it did it was just - it, it just got rid of the impurities in my blood system. Yeah.

Lisa takes the position of agreeing with the use of healers to treat hypertension. Even though she sought healing on several occasions from healers, she remains astonished by the benefits of working with a medicine keeper. This was most evident when she states, "One of them actually brought my high blood pressure down if you can believe it." I also see the parallel to a biomedical framework of health imbedded in Lisa's interpretation of an Aboriginal approach to health. For instance, she describes drinking tea as an elixir to cleanse her blood. Consuming tea to improve wellness aligns with a traditional biomedical framework of health where focus on illness prevails and treatment consists of finding the best antidote for the ailment. Turton (1997) referred to such Aboriginal treatment strategies as "practical knowledge" used by Elders.

Medicine wheel. I admit to being surprised by the disinterest the respondents expressed with regard to pursuing traditional healers or medicine keepers for healing one's hypertension. Aside from Lisa, all the respondents were actually opposed to the involvement of traditional healers, or were ambivalent about their involvement and responded with skepticism and doubt regarding the genuineness of certain so-called healers. My bias that the respondents would be oriented toward traditional Aboriginal healing methods was based on previous findings from the literature and my experiences of undergoing 'Aboriginal awareness training' for health care workers. Such training educates health care workers about an Aboriginal way of understanding health, including understanding how our colonial past has shaped the present. During my analysis and even while writing the chapters, it was enlightening for me to realize that there was mistrust toward some of the Elders or traditional healers in the city. My assumptions were tested and my ignorance exposed.

I spent a great deal of time pondering these issues and my biases. In doing so, I again realized that I was examining the Aboriginal worldview of health through a narrow lens. I made an assumption that Aboriginal people would find it appealing to seek out traditional healers, ceremonies, and teachings, which was mostly unsupported by my findings. When I thought further, I realized I needed to go back to theory. I did not need to learn the specific Aboriginal teachings, such as knowing which type of tree bark made the best tea for a particular ailment. Instead, I anchored myself in my understanding of the medicine wheel. Doing so revealed many examples of more subtle ways in which the respondents grounded and aligned themselves within an Aboriginal framework of health.

Specifically, I resumed thinking about the holism of health, specifically, the understanding that health is achieved only when all four quadrants of the medicine wheel –

emotional, physical, spiritual, mental -- are in balance (CIHI, 2004; Hunter et al., 2006). When orienting toward treatment for a specific disease, all four quadrants need to be considered as part of treatment (Hunter et al., 2006). I had been preoccupied with, and maintained my focus on, the physical realm of functioning, even in my exploration of traditional healers, likely out of the habit of relying on the dominant biomedical framework of health. For instance, I was preoccupied by notions of medicine keepers providing remedies for ailments, in the same way that pharmaceutical substances function. However, according to Arnold and Bruce (2005), concepts such as harmony, interconnectedness, balance, and interrelatedness are all Aboriginal values embedded in this worldview. When I expanded my understanding of Aboriginal health to include these values, I was able to see more clearly the ways in which some of the respondents aligned with such values or, one might say, the traditional teachings.

The following excerpts illustrate the incorporation of such values and the ways in which the respondents adopted a medicine wheel approach toward their health. In this first excerpt, Justin speaks using the terminology of the medicine wheel.

Take these medications, like you know, is there a plant I can eat, you know, these types and I guarantee there's something out there that would definitely work towards that end. Combined with healthy lifestyles and I think meeting the criteria in the circle, the four pieces, like the spiritual, the mental, the social and physical. Try to get those under control and I think currently I'm in a state of imbalance. And I need to fix that and it's just - I love how it can be thought of as a simple thing. It's so simple to do, no it's not. It's really difficult. It takes a lot of work and time. And it's a lifestyle change.

Justin identifies that an imbalance of the four domains of the medicine wheel has affected his health. In doing so, he recognizes that hypertension is more than just physical illness.

However, he highlights that the emphasis on balancing the four quadrants in the medicine wheel is over-simplified and perceived as an easy task when in actuality it is an ongoing struggle.

Similarly, Colin explains how he prefers to orient toward holistic and natural approaches to health.

[My physician and I are] trying more homeopathic, holistic, natural medicines rather than the prescriptions and I'm all in favour of that. I'm too new at it yet to have a good handle on it. It has to do with diet. Diet and meditation, and some deep breathing exercises - I have to go pick the stuff up yet from my health food store - oils, fish oils or something I think is what it is. Some sort of - and he said do you like seafood I said no. Because there are some things in there that he's confident will lower it. And I don't have to lower it much, it's just a little bit to bring it back down and then I'm okay again, so.

This excerpt is set apart by the inclusion of meditation and deep breathing exercises as prescribed by Colin's physician. Although low sodium diet supplemented by the addition of fish oils is well validated in the literature as an effective way to reduce blood pressure (Appel, Miller, Seidler, & Whelton, 1993; Mancia et al., 2007; Morris, Sacks, & Rosner, 1993), spiritual and relaxation methods are seldom addressed in the biomedical approach to treating hypertension.

Lisa describes seeking out another form of alternative health.

Interviewer: And have you ever explored non-medical forms of health?

Lisa: Umm. I'm doing that like I said doing Reiki treatments now? Umm. Or receiving Reiki treatments uh what else. Umm. Pretty much - that. Oh yeah, I did a um what they call I uh acupuncture that one time. And - I don't know, I don't think it really helped that one. I didn't really see a difference. (Interviewer: But the Reiki.) Reiki - yeah.

Urban Aboriginal Peoples and Hypertension

Interviewer: And are you getting Reiki treatments for your high blood pressure or for other reasons?

Lisa: Other reasons, I'm getting um - what they call I uh - I have uh cysts. And one of them nearly burst? You know this past, this past year and I think that's why I'm my blood pressure's high right now 'cause I'm just recovering from all that. Yeah. And I uh - yeah.

Although Reiki and acupuncture are East Asian rather than traditional Aboriginal methods for healing, Lisa reports how she is using such methods to heal the imbalances in her body: a cyst and hypertension. What is particularly salient, though, is how she constructs her high blood pressure being a result of the cyst. In treating the cyst with Reiki, she inadvertently treats the hypertension, which I interpret to be mediated by stress. Here, she emphasizes the interrelatedness and interconnectedness of all things which very much align with Aboriginal values and a medicine wheel framework for health.

Kim addresses the concept of collectivism in the treatment of hypertension.

Maybe we should get awareness out by...like for the exercising and everything ummm they have a food fun and fitness here, but that's basically mainly about diabetes 'cause they test your sugars and stuff like that. But actually if you can have like, 'cause I know at Shopper's they have those blood pressure machines, but if you had a group like that where you could actually get together and actually work on you know your blood pressure, getting everything lowered or whatever, it would probably help.

Kim emphasizes the concept of community and social engagement in activities such as exercise. Such perceived social engagement during health interventions has been found to strengthen success (Cohen, 2004; DiMatteo, 2004). The role of community is a strong Aboriginal

value in Canada. Kim's suggestion is holistic and emphasizes the interconnectedness of people, going beyond just a physical approach to treating hypertension. The benefit of social support to improving health has been well supported by the literature for the past three decades (Cohen, 2004; Thoits, 2011).

Along with collectivism, Ben addresses the impact of combining different facets of the medicine wheel.

Ben: I think not treating myself too good. I think I like being healthy. I like being healthy.

Interviewer: In your body, in your mind or both?

Ben: Body-mind. And for me, running and probably more walking, gives me that feeling, and you meditate more when you're running. You meditate more, and you find nature closer to you.

Ben is referring to physical forms of exercise such as running and walking. He constructs physical activity as spiritual and as helping one connect with nature. His understanding demonstrates the difference between running for fitness and running as part of a holistic health experience.

Emotional balance. One of the four quadrants of the medicine wheel is emotional balance. Emotions can be neglected in medical settings, as the focus tends to be placed on the patient's physical functioning. According to the Indigenous Peoples' Health Research Centre (2006), it is understood that the psychological and emotional trauma endured by Aboriginal people as a result of colonialism and residential school experiences leads to physical disease. Likewise, Garro (1988) found that the Ojibway respondents in her study endorsed stress and worry as the primary cause of elevated blood pressure. Even though addressing the emotional

imbalance led to wellness and health, the respondents still viewed hypertension as a physical disease (Garro, 1988). I wondered how the respondents in the present study regarded their emotional health, particularly given my interest in the relation between anger, depression, stress, anxiety and hypertension as documented in the literature (Bosworth, Bartash, Olsen, & Steffens, 2003; Davidson, MacGregor, Stuhr, & Gidron, 1999; Mills, Davidson, & Farag, 2004; Spicer & Chamberlain, 1996; Yan et al., 2003).

During the focus group, we addressed psychological and emotional health. The following excerpt captures one of several discussions regarding stress and emotional health.

Interviewer: Right. And one thing that both of you said quite strongly is that stress makes your blood pressure go up right? Is that something that you ever talk to your doctors about?

Celeste: Oh yeah, I just went and saw my doctor last week. I'm just in a real deep stressful level right now, depressed. I think that's what causes my blood pressure to go up too. I'm just around a lot of stress right now in my life. Well my doctor's got me on stress pills which doesn't really help at all. I feel okay for a while but I still get stressed no matter what. But I think that's, to me, I feel like that's the main reason why I have high blood pressure is related to stress.

Interviewer: Yeah, and stress is kinda a weird thing. Seems like something you wouldn't treat with a pill right?

Celeste: Yeah, and the pills I'm taking for stress, now I've gotta take them for the rest of my life too, with the high blood pressure pills.

Celeste acknowledged that high stress levels and depressed mood are the main contributors to her high blood pressure. Examined through a medicine wheel framework, her emotional imbalance leads to her physical imbalance. Therefore, she reacts strongly to the use of medication to treat elevated levels of stress. Treating emotional imbalance with medications seems illogical under a medicine wheel framework.

Later, the focus group discussion around stress continues:

Interviewer: Like if we're talking about stress again and you guys are saying it's stressful to live in poverty or to take care of kids or whatever it is that's stressful and the doctor says "well just take a pill," that doesn't change your situation right? [Celeste: No]

Kim: You still get stressed out regardless. Still have those problems regardless. And it doesn't matter if you have if you're in poverty or not, it's like everyday life. With me, like I'm a constant worrier. You know and you know and I'll sit there and my boys will be playing, throwing the ball around I'm like what if they bust the window or what if they do this or you know. And it's like constantly like what if this happens. Checking everywhere trying to make sure they're okay; meanwhile I'm like ahhhh. Like I'm a frazzled ball and I'm like okay.

Interviewer: So, to reduce stress in your life, it's not to take your boys away or have less noise 'cause that's not possible.

Kim: No, not at all.

People's lives can be chaotic and stressful; this stress can contribute to or exacerbate physical illness. Kim eloquently invokes the social determinants of health, notably referring to

the well established relation between income and health status (Raphael, 2007, 2009). As such, life situations that create stress cannot be simply erased to treat hypertension. Treatment must be multi-dimensional and able to meet the complex needs of each patient.

Likewise, Catherine confirms the complexity of factors contributing to hypertension.

Interviewer: Do you think high blood pressure is a big problem for Aboriginal people specifically?

Catherine: Yeah. Yeah.

Interviewer: Why do you think that is?

Catherine: I don't know. It's a lot of stress. It's a lot of stress being - I don't know. A lot of things, there's a lot of different things coming at people different ways and like a lot of people have stress with their kids, the - getting the - uh, the drugs are hard out here. As they're everywhere. Girls are working, guys are - selling drugs and your kids are getting in trouble and there you're sitting home wondering what the kids are doing and then even your grandkids and - your health. That's a lot. That's a lot of stress right there, man. 'Cause when my son comes here and I'm wondering where he is - I won't let him go unless I'm with him. But the other day I let him go and they're at Extra Foods. And that, that, that's a busy street. Yeah.

Interviewer: Okay. So mostly stress eh?

Catherine: I think it's a lot of stress. It's the way they eat. It's the way they eat, too. It's all the things....

This excerpt exemplifies that poor health is caused by many things other than physical causes. Catherine touches on lifestyle conditions as well as stress and poor nutrition as

contributing factors to hypertension. She also addresses valid fears regarding access to drugs and the unspoken vigilance about addiction that has caused havoc for so many individuals within Aboriginal communities. In order to truly understand the impacts of hypertension, we need to remain broad and the medicine wheel provides a helpful framework encompassing the broader issues that have an impact on health.

Conclusion

In this chapter I examined issues related to hypertension treatment, adherence to treatment, and worldviews of health. I was interested in going beyond the treatment recommendations conveyed by physicians, considering, instead, the ways in which the respondents oriented toward treatment. This orientation included the reasons for adhering to or resisting medication. Similarly, to ensure I captured all the layers embedded in understanding respondents' attitudes and action toward treatment, I also explored the respondents' worldview or understanding of health and how it fit within the dominant biomedical or Aboriginal framework of health.

When attempting to understand the role of an Aboriginal worldview, my initial understanding was superficial, narrow-minded, and limited. Specifically, I made the assumption that Aboriginal health consisted solely of working with Elders, healers, and medicine keepers. By challenging my assumption, I was able to broaden my perspective and clearly see that an Aboriginal worldview of health consisted of so much more than simply accessing services with medicine keepers. When I expanded my understanding to encompass a medicine wheel framework, I was able to see the connections between respondents' attitudes and beliefs toward treatment and the ways in which they managed to integrate the two worldviews. Though not evident at first review, it became clear that some respondents maintained alignment with values

of both the biomedical and the Aboriginal worldview of health and healing for the treatment of hypertension.

Chapter 6: Action Research

In this chapter, I describe how I actively engaged with the research findings and disseminated the results in an effort to draw awareness to the issues surrounding hypertension.

Action Research: Suggestions for Improvement

All respondents in this study provided specific suggestions of ways to bring awareness to hypertension among Aboriginal people in Saskatoon. Of note, I specifically directed the latter part of all interviews to a discussion of broad-based prevention for hypertension. I did so as I wanted direct feedback from the respondents on strategies for prevention. These suggestions were compiled and then discussed with the respondents at the time of the focus group as a way for everyone to reengage with the analysis. In addition, these action research suggestions were discussed separately with members of the Aboriginal advisory group. Although not all the participants' suggestions were taken up as a deliberate action research strategy in this dissertation, some are examined here.

Overall, naming suggestions for improvement tended to generate discussion about barriers to care, including limited access to resources. For instance, there are no existing intervention programs in Saskatoon specifically for hypertension. Individuals, instead, access diabetes or cardiac prevention and management programs, such as the Food, Fitness and Fun program, the LiveWell with Diabetes program, or the LiveWell cardiac program (Saskatoon Health Region, nd). Nevertheless, such programs often have a fee and tend to be located in a wealthy district of the city, off a freeway, away from public transit, or in areas accessible only by vehicle.

In addition, the Heart and Stroke Foundation of Canada (HSFC) has excellent online and in-office resources about hypertension. I provided copies of such resources to respondents at the

focus group and they were surprised to read the information provided in the handouts. For instance, one respondent noted that she had never realized that high sodium was a risk factor for hypertension. Another noted that she had not realized that sodium meant salt. She further stated that she was shocked to learn that canned food, lunch meats, and pickles were particularly high in sodium and that high consumption was not encouraged for individuals with hypertension. Instead, she mentioned that she had only been informed that she should avoid fried and greasy food.

I had a surplus of copies of such resources at the focus group and the participants in attendance requested all the available copies. The respondents expressed that the bus ride to access the HSFC office downtown or the necessity of having internet access with a printer made this resource inaccessible. Consequently, such discussions highlighted clear suggestions for future programs and services: locating resource and programming facilities in the target communities is crucial. If programs are going to be situated elsewhere, then public transit and fitness facility memberships should be subsidized.

Likewise, access to healthy food has been an ongoing challenge for citizens of Saskatoon's core neighbourhoods who do not have a vehicle, and municipal planners need to ensure and prioritize such access (Woods, 2003). The respondents also highlighted such barriers. Additionally, increasing access to medical services, including blood pressure machines, could improve hypertension awareness and treatment. These ideas generated by the respondents, although not novel or surprising, reaffirm the importance of eliciting and integrating input from the communities in decisions about interventions along with locating vital services to improving health within the core neighbourhoods.

Respondents brought forth another suggestion: the most progressive way to make significant change in Aboriginal people's health status is to rebuild a community. Despite the vague nature of this suggestion, rebuilding a community takes into account that health is holistic, influenced by generational factors and the complex interplay between the social and Aboriginal determinants of health. Specifically, community gardens and food sharing programs enhance food security among communities (Child Hunger Education Program, nd; Woods, 2003). Likewise, child programs, youth activity programming, and affordable housing subsidization influence health across the lifespan (Reading, 2009). By implementing changes at the community and family level, such community intervention has the potential to shape how children learn about their health and to promote healthy lifestyle choices throughout the lifespan. Hence, interventions targeting children's health, including prenatal education, parenting classes, early intervention child nutrition and exercise programs can have positive and lasting effects for many generations. Further, income support, food security, housing, employment, education, and safety are worthy areas for intervention, as they help to rebuild community (NAHO, 2006).

My findings raised the question of resources, ones as straightforward as accessible information about hypertension. Despite the enormous money that goes into the provision of health care, Aboriginal people with hypertension are, at times, ill informed. Creativity might be required to address the barriers to health information and improvement for Aboriginal peoples. For example, the health care system could produce good material (such as pamphlets outlining what sodium is and how to understand food labels); have nurses available to interpret the physician's diagnosis with more and timely instruction; provide services such as support groups of like-minded people to increase understanding, an 800 phone line for further explanation,

clinics offering a pharmacy brown-bag lunch where patients arrive with their medications and can consult in depth with pharmacists.

Currently, much of these types of interventions are not available or not made available despite the resources that exist in the health care system and despite the need expressed by patients. A good starting point would be to encourage Westwinds Primary Care centre, Westside clinic, and Saskatoon community clinic (the main primary care clinics in the target area) to offer some of these services.

Taking Action

Initially, I analyzed the interview data and created themes that I felt represented the respondents' views. I took these findings back to the participants during the focus group for discussion. Such discussions helped me elaborate on the preliminary findings and add new dimensions. However, I did not emerge from the focus group with a clear understanding of how to implement an action research component. When I directly asked the research questions (i.e., What changes need to be made to improve rates of hypertension in Saskatoon's Aboriginal communities? And what is the most effective manner to create these changes?), I found that the participants struggled to respond. It seemed to me that they were uncomfortable with suggesting intervention ideas for groups of people and, instead, were more at ease addressing their own situation. As such, at this juncture, I realized that I needed to return to my analysis and review the latent meanings from the interviews.

After analyzing all the findings from the individual interviews and subsequent focus group, I no longer had contact with the respondents. I did, however, maintain contact with the Aboriginal advisory group and consulted with them as needed. At this time, I had also moved away from Saskatoon to complete my pre-doctoral residency in another city. As such, I felt

disconnected from the Aboriginal communities and realized that the action research needed to be not only meaningful, but also realistic and feasible.

At this stage, I envisioned that I would create policy suggestions which I would submit to health policy analysts within the provincial Ministry of Health. This goal felt appropriate as it was my attempt at both midstream (preventative) and upstream (population-based via healthy public policy) interventions (McKinlay, 1998). In my efforts to carry out this goal, I began to read about health policy. Shortly into this ambitious undertaking, I realized that I was veering too far away from the scope of the present research. It became evident to me that to suggest policy recommendations of substance, I required much more of a formal background in this area. Further, I would have no way of evaluating the recommendations I had made.

In order to translate the findings of this dissertation into meaningful practice, I consulted with the Aboriginal advisory group and an Aboriginal health policy analyst with the Saskatchewan Ministry of Health to discuss more appropriate ways of dissemination. Once I decided on my dissemination strategies, I wanted to ensure my actions were appropriate and helpful.

First, plans for dissemination included having an article written by local Aboriginal newspapers about the research and my findings. Eagle Feather News and Sage newspapers have expressed interest in publishing an article in the near future. I successfully published a summary of the research in Indigenous Times newspaper (Calverley, 2012) (see Appendix N).

Then, I wrote an executive summary that will be electronically distributed to Aboriginal health researchers, the Indigenous Peoples Health Research Centre (IPHRC), and professors within the Department of Community Health and Epidemiology, Department of Internal Medicine and Cardiology, Department of Family Medicine, and the College of Nursing at the

University of Saskatchewan (see Appendix O). The IPHRC, as previously mentioned, is part of a national network of Aboriginal research agencies. As such, in providing the IPHRC with my findings, I will be sharing this knowledge with local researchers as well as other national groups within the ARnetS who might find the summary useful or applicable. My rationale for disseminating the summary to faculty in the Department of Community Health and Epidemiology is that this department offers a course to medical students about the social determinants of health. I want to ensure that current, local research is being considered in the training of health care professionals.

Lastly, I attempted to arrange to meet with interested parties at the Saskatchewan Ministry of Health and provide them with a brown-bag lunch/informal presentation of my findings with an opportunity for them to ask questions and engage in a dialogue. I selected the ministry as it was my way of taking the findings beyond the immediate, local context. In meeting with policy analysts through the ministry who are engaged in the urban Aboriginal strategy, my hope was to disseminate this knowledge to many people who shape important provincial health decisions. However, due to difficulties in coordinating schedules, I was able to meet with only one health policy analyst who informed me that there had been reduced interest from the Ministry of Health given that the group mandated to deal with urban Aboriginal policy is responsible for all components of well-being, including health, housing, and employment. Consequently, although they found my findings interesting, they considered hypertension to be too specific to be addressed at the provincial level. This discussion fostered my realization that I had not clearly indicated the links between hypertension and diabetes and, specifically, that successfully reducing one's blood pressure is one of the most effective interventions in reducing rates of mortality and cardiovascular complications of diabetes (Campbell et al., 2012). The

policy analyst also informed me that, due to recent economic tightening within the federal government, the National Aboriginal Health Organization had disbanded (Barber, personal communication). As such, within all levels of government, financial resources to fund Aboriginal health are limited. Unfortunately, the timing of this project is less than ideal as the potential for change in the present political and economic climate is reduced. I understand, however, that this work has initiated a dialogue about hypertension that was under-explored for the last 24 years. My aim is to continue to share these findings and encourage others to focus research and practical initiatives on hypertension.

Chapter 7: Discussion

“To see from one eye with the strengths of Indigenous ways of knowing, and to see from the other eye with the strengths of Western ways of knowing, and to use both of these eyes together.”

Mi'kmaq Elder Albert Marshall (Institute for Aboriginal Peoples' Health, 2012, p.1)

The primary objective of this dissertation is to contribute to a better understanding of urban Aboriginal peoples' health in Canada by examining the respondents' attitudes, beliefs, and experiences toward diagnosis and treatment of hypertension. A second objective is to commence a community- and patient-driven dialogue regarding suggestions for improvement to current models of health and hypertension intervention for Saskatoon's urban Aboriginal citizens. Using a combination of individual interviews and a focus group, I gathered qualitative data which provided information from the respondents' perspective. Rather than stating expected findings as generally found in traditional positivist dissertations, this dissertation is more exploratory in nature and I favour diversity, contradiction and unforeseen responses in the data.

Summary of Findings

In chapter three (the first of the three analysis chapters) I investigated the ways in which the respondents oriented themselves toward hypertension. My analysis focused on dominant moral underpinnings of health and the health promotion framework which emphasize individual responsibility. The findings in this chapter reveal the respondents' adoption of the individual responsibility discourse (i.e., blaming the individual); even when the respondents challenged this discourse, their arguments were still organized around the biomedical and individualist frameworks of health. Such prominence accorded to the individualist framework accompanied by moral and emotional sequelae is well supported by past literature (Crawford, 1998, 2006;

Crossley, 2002; 2003; Townsend, 2009). This literature helps to remind us that issues of morality are broad and include political, economic, historical, cultural, and social influences.

Since the respondents predominantly adopted a biomedical, individual responsibility discourse toward health, they did not explicitly address larger societal, economic, or political issues affecting their health. The prominence given to the individual responsibility discourse in these findings contrasts with the robust research evidence suggesting that health is strongly influenced by the social and Aboriginal determinants of health --especially income-- rather than individual factors (National Aboriginal Health Organization [NAHO], 2006; Public Health Agency of Canada [PHAC], 2003a, 2003b; Raphael, 2009; World Health Organization [WHO], 2008). However, when I looked at what was not being said explicitly and the latent meaning of the respondents' words, the data revealed many references to the social and Aboriginal determinants of health. I am also aware that not all determinants were mentioned by the respondents in the present research. For instance, of the 14 named social determinants of health: gender, disability, and employment and working conditions were not described as being factors impacting the respondents' health. In contrast, poverty, Aboriginal status, and food insecurity were highlighted as contributing factors to the onset and maintenance of hypertension. Likewise, some of the Aboriginal determinants of health, specifically globalization and territory, were not invoked by the respondents.

The focus on blaming the victim and individual responsibility ultimately steers attention away from an analysis of macro-level forces such as poverty, unstable housing, and food insecurity that generate and maintain the individual's poor health habits (McKinlay, 1997). Further, the societal imposition of responsibility for health on the individual seems misaligned, as hypertension is known to be more prevalent among certain cultural minority groups in Canada

and the USA, including Aboriginal people and African Americans (PHAC, 2004; Kaplan, Chang, Newsom, & McFarland. 2002; Scherwitz & Rugulies, 1991). Nevertheless, for the urban Aboriginal respondents in this study, –as revealed by the findings of the present research-- the responsibility for health remains imposed on the individual.

In the fourth chapter I examined how lay and expert knowledge is negotiated. I argued that most lay persons in this study are well informed, savvy, and hold expert knowledge of their health primarily within a biomedical framework. These findings are consistent with past research on expert patients (National Health Service, 2010). However, the respondents desired more specific and accessible information about hypertension and treatment issues. Although some of the respondents in this study were highly resourceful and mostly willing to seek out expert knowledge or highly technical information, not all had access (e.g., transportation, time, energy, etc.) or the desire to pursue such information. Consequently, lack of patient access to information was a prominent barrier to health improvement. Further, my analysis revealed latent descriptions of the influence of socio-cultural, political, colonial, and economic factors related to health, confirming findings from past research (Canadian Institute for Health Information [CIHI], 2004; King, Smith, & Gracey, 2009; Marmot, 2005; Mikkonen & Raphael, 2010; Raphael, 2009).

I also found that, according to the respondents, medical expertise held by physicians remains privileged over lay knowledge. These findings highlight and support the persistence of power imbalances and colonial exchanges within health care encounters with Aboriginal patients, as revealed in past literature (Billie Littlechild, Este, Galabuzi, & Bassey Etowa, 2011; King et al., 2009). In addition, the examples of colonialism provided in this dissertation support the ongoing struggle for Aboriginal patients to be deemed equals within the context of health care encounters (Billie Littlechild et al., 2011; Canadian Medicine News, 2009; Elliot & Leeuw,

2009; Hamil & Dickey, 2005; Stephens, 2009; Towle et al., 2006). Foucault (1980) contended that knowledge equals power; yet while respondents in this study demonstrated their experiential and expert knowledge, their level of power within health care encounters remained reduced.

Although privileged, physicians' knowledge remains incomplete without complementary patient knowledge, as outlined in the shared-decision making model (Lidskog, 2008). Further, interventions ought to encourage more active participation from the patient both during individual encounters as well as at the level of policy development. Such efforts might serve to decolonize knowledge and increase shared understandings of barriers to health care.

In the fifth chapter I explored how respondents approach the treatment for hypertension. Overall, my findings suggest that the respondents generally oriented toward a biomedical understanding of hypertension treatment. The findings also highlighted that colonialism persists, whether during health care encounters or simply in the assumption that Aboriginal patients have special needs during health care encounters (Billie Littlechild et al., 2011; Browne & Varcoe, 2006; King et al., 2009; Smith, 1999). These findings align with previous research. Specifically, Garro (1988, 1995) identified that the recent explosion of chronic disease in Aboriginal communities (e.g., hypertension and diabetes), labeled as "white man's disease," was the result of colonialism as the colonizers introduced different food, along with altered cultural values and practices which are now understood to lead to chronic disease. Due to the recency of white man's diseases, local traditional healers lacked the ability to treat them and therefore biomedical treatment was often deemed most appropriate for such modern conditions. (Garro, 1988). Garro's findings contributed a foundation for interpreting the results of this study, particularly the ways in which hypertension is a consequence of colonialism. However, the present study

demonstrates that, in the respondents accounts, colonialism persists in health care and, notably, in the treatment of hypertension.

Past research has also consistently supported the importance of Aboriginal values and frameworks for understanding health (Arnold & Bruce, 2005; CIHI, 2004; Hunter, Logan, Goulet, & Barton, 2006). Such Aboriginal worldviews of health emphasize the importance of ancestors, family, and community; therefore interventions within Aboriginal communities should contain a communal and spiritual focus, including emphasis on connection to nature (Mussell, 2006). Consistent with previous research examining Aboriginal models of health, the respondents in this study were mixed in whether they endorsed the broadening of interventions to include all the dimensions of the medicine wheel (Arnold & Bruce, 2005; CIHI, 2004; Hunter et al., 2006). The present findings suggest that interventions for urban Aboriginal people should retain traditional, biomedically-focused components (including patient education regarding options for hypertension treatment as well as lifestyle modifications) with the addition of emotional and spiritually-based components when desired by communities or on a patient-by-patient basis.

Overall, the findings from the present research confirm the prominence of a biomedical understanding of health. Likewise, diversity and variability existed in the extent that the Aboriginal respondents' beliefs and orientations toward their health was understood from a biomedical framework. Such diversity is crucial to consider during health care encounters as a single approach will not likely suit the needs of all Aboriginal –or non-Aboriginal-- patients. If a patient is hoping for a biomedical approach (versus a holistic, medicine-wheel approach) to treating hypertension or is seeking expert knowledge, such information would be pertinent for the health care provider. Promoting discussion of patients' beliefs toward disease and attitudes

about treatment for hypertension is tremendously important for health care providers; such discussions might reveal potential barriers to adherence.

Implications

The present analysis has implications for the nature of our current approaches to health and for future intervention. The findings in this study revealed that speaking the language of biomedicine --whether through adoption of self-responsibility for health or orienting toward medication and lifestyle modifications to treat hypertension—was familiar for respondents. In spite of apparent stigmatization and shaming of poor health, Aboriginal peoples are not passive recipients of disease. Rather, the findings from the present research highlight that adopting the dominant biomedical discourses of health led to the respondents feeling empowered and powerless, yet always responsible for their own health.

The findings also revealed that the respondents speak the language of biomedicine, particularly through their demonstrations of technical and expert health knowledge; in spite of this, having sophisticated biomedical knowledge did not necessarily equal adherence to treatment, a finding not unique to this study. However, findings from the present research provide valuable insight that adherence is confounded by other factors, such as self-blame for poor health, stigmatization, access issues, colonialism, and power imbalances. Therefore, in order to enhance the effectiveness, efficacy, and significance of current interventions, researchers and health care practitioners need to be sensitive to these factors within health care encounters with Aboriginal patients.

The capacity for Aboriginal peoples to orient themselves to a Westernized, biomedical discourse should not imply that all encounters are rosy. Even when respondents oriented toward a biomedical framework for diagnosis and treatment for hypertension, their experiences varied.

For instance, shame, ambivalence, anger, and disempowerment resulting from experience with health care encounters and biomedical frameworks for health were described in my findings. Therefore, adoption of biomedical discourses of health might be both beneficial and detrimental for urban Aboriginal peoples.

Previous research by Browne and Varcoe (2006) has raised comparable issues, notably that the tendency to treat Aboriginal people as having “special” or unique health needs might lead to stereotypical, rigid, and simplified understandings of the role of culture in health. This conclusion suggests that our attempts to adopt culturally sensitive practices in health care might be yet another colonial way to perpetuate Aboriginal people as “others” with different beliefs and practices. In essence, these findings suggest that there exists a disconnection between physicians attempting to practice with increased cultural sensitivity and how patients perceive such information during health care encounters, particularly when the most culturally appropriate approach might be to simply respond openly to the patient regardless of race. These findings reflect the diversity among Aboriginal people in Canada and remind us that health care practitioners need to remain open to determining the most suitable approach for each individual patient, and not assume that all Aboriginal people are alike.

The implications of these findings are striking: individual efforts toward health promotion are limited if health is significantly influenced by social determinants and macro-level factors. Such revelations align with the vast body of research that consistently supports the greater need to expand the responsibility for health beyond the individual. It is apparent that downstream interventions, comprising mainly treatment efforts, are necessary to assist those individuals presently affected by disease. However, if we strive to shift the cultural discourse from that of a reactionary approach to an approach valuing health and wellness, we must

endeavour to include midstream and upstream interventions. As a prime example of the limited influence of current health promotion efforts, Campbell (2004) highlighted that 75% of individual behaviour change is unsuccessful, especially with individuals from moderate to lower SES backgrounds. As a result, Campbell (2004) suggested that we should focus our efforts on the factors known to successfully impact behaviour change: altering popular norms or discourses and enhancing community support for change initiatives. Ideal interventions would therefore jointly consider individual factors along with macro-level factors that contribute to urban Aboriginal peoples' health (Herr & Anderson, 2005). To address these broader barriers, this study is helpful to inform future programs of the importance of socio-economic factors. For instance, providing services within walking distance or access to healthy food within low-income neighbourhoods needs to be prioritized along with medical provision.

Likewise, individual health promotion efforts also need attention. Specifically, attention being given to mental wellness and stress reduction is minimal, despite their demonstrated relation to physical health. Therefore, there is an increased need to expand the role of psychology in primary care. In sum, this study highlights the need for health promotion to address both individual needs and also barriers at the population- level which are equally influential in determining health.

Possibilities for Future Research- Strengths and Limitations of the Present Research

While conducting this research and writing this document, I learned many lessons. This study highlights several factors that future Aboriginal health researchers should consider in order to strengthen the validity and trustworthiness (robustness) of their findings.

As described in the literature, for outside and non-Aboriginal researchers, taking time to build and foster relationships with Aboriginal communities has proven to be fundamental to the

development of successful research endeavours (Canadian Institutes of Health Research [CIHR], 2007; IPHRC, 2004; Smith, 1999). The consideration of community needs also provides external validity and valuable community input and perspective (Benoit, Jansson, Millar, & Phillips, 2005; Green & Glasgow, 2006). Future research projects will similarly benefit from efforts to build trust, mutual respect, and open communication. Too few psychological studies have examined the impact of community-based research or consulted with urban Aboriginal communities. However, research is more credible, robust, and valid when respondents are involved in what is being researched and how the research is conducted. Therefore a community-based, action research project is highly recommended as the most suitable methodology when conducting research with members of these communities. The aforementioned reasons highlight how this dissertation, by adhering to rigorous standards of conducting Aboriginal health research, is an important contribution to the literature.

In addition to working directly with communities, collaborating with the Aboriginal advisory group significantly contributed to the strengths of this study. The guidance from members of this group facilitated the cultural appropriateness of this study, recruitment, interpretation of results, and suggestions for action and knowledge translation. Providing an offering of a small pouch of tobacco to the Elder was suggested to me as it helps to demonstrate respect. I would undoubtedly recommend this practice to all researchers involved with Elders.

The response to my posters was very telling and indicated a strong desire for people to share their stories and experiences. It was also helpful to have the names of the members of the Aboriginal advisory group directly on the poster and to have the poster distributed through the electronic databases of prominent Aboriginal agencies. Consequently, these two unique features,

I believe, helped to establish the legitimacy of my study, given my status as a non-Aboriginal researcher.

The presence and participation of two Aboriginal advisory group members at the focus group significantly increased my credibility and helped put respondents at ease. These participants also posed challenging questions that expanded the discussion. Collaboration with key informants, spiritual Elders, and community members in a group format is a progressive way to ensure one's design, methodology, and methods are facilitating ethical research that is appropriate to the community with whom one is working. Aboriginal, community-based, key informants should also be involved in policy analysis and recommendations put forth to government.

Consistency between these findings and existing research on Aboriginal health and social determinants of health suggests that the current findings are practical and meaningful. Therefore, the findings inform the following general suggestions for the development of future intervention programs.

- Provide accessible programming services for hypertension in core neighbourhoods where need is greater.
- Increase collaboration among researchers, community members, policy makers, and health care providers by instituting working groups as a mandatory component of interventions.
- Encourage program respondents to provide and implement feedback to improve programming.

Urban Aboriginal Peoples and Hypertension

- Train intervention workers to be aware of Aboriginal models of wellness (e.g., medicine wheel framework) and to encourage respondents to approach health as beyond the framework of physical disease and individual responsibility.
- Increase both physician and patient awareness about the limitations of health care encounters in fulfilling patients' health and wellness needs.
- Include counsellors, Elders, and others who can assist in supporting the social and emotional well-being of Aboriginal respondents.

Further research and program evaluation will be worthwhile to clearly identify interventions that are most effective at decreasing hypertension rates in Aboriginal communities in Saskatoon. Similarly, applied research is beneficial in contributing to clinical practice and institutional practices through policy changes (Silverman, 2005). These efforts would likely promote community involvement and practical usage of research findings to enhance trust between communities and academic institutions.

My willingness to go to the people was a major strength of this research. Data collection methods should be convenient, accessible, and comfortable. For instance, the focus group was held in a culturally-appropriate, friendly, and accessible facility. Moreover, honorariums should be used in future research to compensate people for their time and involvement, particularly if a project is more participatory in nature. Honorariums validate and appreciate the participants. I provided food and drink during the focus group as the respondents contributed their time over the dinner hour.

When conducting research with urban Aboriginal communities, culturally appropriate data collection methods should be considered. For instance, all data should be verified by the respondents before proceeding with the analysis. At times, the results of the analysis might also

be reviewed by the respondents. Such strategies inevitably enhance respondent validation and are culturally-appropriate (CIHR, 2007; IPHRC, 2004; Silverman, 2001). Additionally, as urban Aboriginal populations are pluralistic and composed of diverse tribal representation, Métis origin, and individuals who vary in their degree of acculturation, variation between and among respondents should be considered (i.e., age, gender, education, income, degree of acculturation, ethnic origin). In doing so, overt generalizations about Aboriginal people can be avoided.

Rarely does psychological research explicitly state a political agenda, and yet we have expertise in understanding how social and institutional structures affect individual attitudes, beliefs, and behaviours. We have a responsibility to acknowledge the political agendas at play, to work toward social justice and the reduction of inequities, and to translate our data into meaningful and practical action.

Writing about the limitations of biomedicine and the ongoing existence of colonialism in health care is undeniably challenging. Nevertheless, I felt that I needed to broach these topics to convey the resilience and courage embodied by the respondents. Further, a critical theoretical perspective prioritizes an analysis of power and posits that unquestioned and unchallenged power structures perpetuate the status quo.

My involvement in this research was delicate and sensitive. As a non-Aboriginal person, I did not always feel comfortable critiquing Aboriginal frameworks toward health as I was attempting to remain consistent with a strength-based approach. This approach acknowledges centuries of oppression of Aboriginal peoples and demeaning attitudes toward Aboriginal viewpoints. My aim was deliberate: I did not want to contribute to any further shaming of Aboriginal peoples. Instead, in my analysis I strove to provide structure to the views of the participants as constructed during the data collection rather than over-interpret the findings in an

abstract or esoteric fashion. I was committed to discussing only the findings which could be supported by the data. As this study is applied research, it was even more compelling for me to present the findings in a pragmatic and relevant way. Such sensitivity to the process of being an outside researcher conducting Aboriginal health and action research is vital and any researcher wanting to undertake a similar research endeavour requires the commitment to maneuver the challenges embedded in such politically charged research.

In hindsight, I am able to observe certain aspects of the study that could have been strengthened. In attempting to ensure reliable attendance and accessibility, providing child care during data collection is practical and enhances the caregivers' ability to focus on the discussion. As noted previously, I found that the respondents were quite transient; holding the focus group one year after the initial data collection allowed me to complete my preliminary data analysis, yet it also prevented me from retaining contact with all the respondents. There was a significant amount of attrition among respondents one year later. Although attrition is a reality of conducting this type of research, consideration should be given to the time between data collection phases and to maintaining updated respondent contact information.

After extensive consultations with my research team, advisor, colleagues, and the Aboriginal advisory group, I began to understand that in community-based research with Aboriginal peoples, the course is not always as conventional or controlled as in academic settings. I also began to appreciate that attrition signified the reality of life for urban Aboriginal people. Geographic barriers and access issues prohibited several participants from returning to participate in the focus group. I wondered how such factors might also prohibit individuals from managing hypertension. Therefore, the experience with the focus group was more informative of the barriers of broader determinants present than what some of the discussions revealed.

As with other qualitative research studies, the non-experimental design of this study limits my ability to attribute causality. Further, I generated insufficient data to generalize to Saskatoon's urban Aboriginal communities or other related contexts, nor was this my intent to do so. Findings are intended to relate only to the participants in this study. However, the findings might still be transferable to other urban Aboriginal communities, minority groups, or vulnerable persons.

As my main method of data collection consisted of individual interviews, I might have overlooked the social desirability bias. The respondents might have provided socially appropriate responses, particularly as I was an outside researcher and not a member of any Aboriginal community. The inclusion of inside researchers would be beneficial.

In addition, my interview questions prompted biomedically-focused responses, and might have increased the extent to which respondents relied on this discourse. Overall, future studies should consider alternative data collection methods, such as the use of oral and story-telling traditions.

Similarly, in conducting research, one must always be aware of a selection bias in recruitment. Since one of my recruitment criteria insisted on respondents having a confirmed diagnosis of hypertension by a health professional, it is possible that those who participated were oriented toward a biomedical framework of health. Future research could consider working with individuals who suspect they have hypertension or who do not align with accessing biomedical services. Equally, one could examine in greater depth how traditional ways of knowing in an Aboriginal framework are provided to urban Aboriginal people with hypertension.

To enhance the richness of this study, collecting physicians' (or other health care providers') perspectives on health care encounters with Aboriginal patients would be extremely

useful and would enhance the triangulation of the findings. These alternative perspectives would inform us about potential challenges or barriers from the health care providers' point of view. In this type of study, involving front line health workers would enable the relaying of findings from Aboriginal respondents to the care providers. Information gleaned from a focus group with health care providers could add missing, and relevant, information required for the development and/or evaluation of a comprehensive community-based intervention. In order to properly design future programming or policy recommendations, knowledge of the perspectives of various stakeholders in health care, beyond the patient, is critical. Similarly, a formalized needs assessment of local hypertension rates among Aboriginal peoples and barriers to accessing services might also supply information that could positively impact future service provision and serve as collateral evidence for policy makers.

In the introduction of this dissertation, I reviewed mainstream health psychology adherence theories, yet noted that none of these theories currently have been validated for Aboriginal populations. At this juncture, it is conceivable that future research might involve such a validation process. However, my findings suggest that these theories are too limited in their scope to appropriately address the broader factors that influence and determine health status, particularly for Aboriginal peoples. Specifically, Radley (1994) and Stainton-Rogers (1991) identified that such theories are overly reductionistic, overemphasizing the role of cognitions while underemphasizing the social, economic, and political context.

The present study retained a focus on the state of disease, as situated in the physical realm and stayed mostly within a narrowly defined, bodily-based view of health. It would be worthwhile for future research to shift away from the illness experience and instead focus more

on healthism by examining how people feel healthy even while living with chronic disease. The literature needs more studies focused on wellness rather than the state of disease.

The present study included a diverse respondent base with a wide age range. Perhaps not so surprising was that the respondents reflected the epidemiological trend of earlier age of onset of hypertension; about one third of the respondents were in their twenties. It might be revealing for future research to examine the effects of hypertension on younger people as the epidemiological trends shift. Similarly, the respondents varied significantly in terms of their socio-economic standing (SES). The data did not reveal a compelling enough trend for me to analyze SES as an influence. Yet, the literature strongly indicates the effect of income, in particular, as a social and Aboriginal determinant of health. Therefore, future studies might be oriented to exploring this influence in greater depth.

In addition, future research could explore understandings and beliefs about hypertension diagnosis and treatment through a gendered lens. Gender is salient as epidemiological trends demonstrate that the rates of hypertension vary between men and women depending on one's life stage (i.e., pre- versus post-menopause). Likewise, Aboriginal women have poorer overall health status and higher rates of disease than Aboriginal men (Health Canada, 2000; K. Anderson, 2005; Stout, Kipling, & Stout, 2001). I did not analyze the data using a gendered lens, but it is conceivable that gender played a role in the respondents' understanding of health and hypertension diagnosis and treatment. For instance, I wonder whether issues of childcare have an impact on one's ability to manage chronic diseases such as hypertension, or whether female, Aboriginal patients experience health encounters differently than their non-Aboriginal counterparts. It would be relevant to explore whether rates of adherence vary for Aboriginal men

and women or whether gender plays a role in holding expert knowledge or accessing of services. More investigation is needed to clarify the role of gender in Aboriginal people's health.

A barrier to abiding fully by OCAP principles was inherent in this project: I was an outside researcher, and control of this project remained with me and the academic institution to which I belong (NAHO, 2007). Therefore, this study was more aligned with action research than with participatory action research. I attempted to balance the needs of this academic degree requirements and funding body timelines with the communities' needs to the best of my abilities, notably through my collaboration with the Aboriginal advisory group. Doctoral students interested in Aboriginal health research who want to fully honour OCAP principles might choose a dissertation topic that is a portion of an already existing community-based project.

I initially envisioned this project as producing policy recommendations and an actual intervention. Yet, along the way I learnt that the scope of a dissertation is more limited and confined by timelines and other demands. I also realized that as a clinical psychology student, generating policy recommendations is beyond my scope of expertise. As such, I developed a condensed overview for review by provincial and municipal policy analysts who are in a better position to evaluate the feasibility of such recommendations.

Lastly, this study was not an attempt to identify a pan-Aboriginal perspective of hypertension; rather my goal was to inform the literature regarding how a group of urban Aboriginal individuals understood and perceived hypertension and their encounters with the health care system in Saskatoon. Although many of my findings of hypertension and its treatment in terms of a biomedical and individualistic model might not be unique to the urban Aboriginal respondents in this study or to hypertension, the present research adds to the existing literature on urban Aboriginal peoples' health. This study highlights that there remains a

stereotypical view in our society that Aboriginal people want specific “Aboriginal” health services; such views might be deemed condescending or inappropriate by some Aboriginal patients. My findings highlight the diversity of beliefs among urban Aboriginal people, as well as the tendency to adopt dominant discourses toward health.

Moreover, although one could argue that there always exists a power imbalance between physicians and patients regardless of the patient’s background, my findings reveal that this power imbalance can be heightened for some Aboriginal persons due to the history of colonialism and oppression of Aboriginal peoples of Canada. Current health care encounters and practices do not occur in isolation; rather, they are influenced by Canadian history and post-colonial thought. For that reason, this study draws attention to the persistence of colonial and racist attitudes toward Aboriginal peoples in our health care institutions.

Finally, the findings of the present study draw attention to the importance of including community and patient input in the design of interventions and health policy. This point is particularly salient for Aboriginal people as they demonstrate unique health needs and might prefer programming to cater to the diversity inherent in urban Aboriginal communities.

Importance of the Findings

This study informs Canadian health care practitioners of potential barriers for urban Aboriginal peoples to accessing health care or adhering to treatment advice, from the patient’s perspective. This dissertation adds knowledge to the sparse literature on Aboriginal people and hypertension, particularly the complexities of urban communities and the dynamic interplay between dominant discourses of health and traditional ways of knowing. The findings illustrate clearly that health care workers should be wary of making assumptions regarding Aboriginal

people. Instead, an appreciation of the diversity of patients' perspectives and frameworks for understanding health is required.

Knowledge highlighted in this study also may help to inform policy recommendations and support the development of future risk-reduction programs, interventions, and health promotion activities tailored to meet the needs of Aboriginal peoples in Canada.

This study promotes cost-effective, preventative, effective programming, including downstream, midstream, and upstream levels of intervention, accompanied by rigorous evaluation to expand the literature in this area. Presently, this study remains the only known Canadian research project investigating hypertension in urban Aboriginal people. By providing in-depth, qualitative data, I have begun to address this gap in knowledge and provide descriptive and rich accounts of the barriers and successes of current health care practices and institutions.

References

- Abbott, P. J. (1998). Traditional and western healing practices for alcoholism in American Indians and Alaska Natives. *Substance Use & Misuse*, 33, 2605-2646.
[doi:10.3109/10826089809059342](https://doi.org/10.3109/10826089809059342)
- Ajzen, I. & Fishbein, M. (1980). *Understanding attitudes and predicting social behaviour*. Englewood, NJ: Prentice Hall.
- Ajzen, I. & Madden, T. J. (1986). Prediction of goal-directed behaviour: Attitudes, intentions, and perceived behaviour control. *Journal of Experimental Social Psychology*, 22, 453-474. [doi:10.1016/0022-1031\(86\)90045-4](https://doi.org/10.1016/0022-1031(86)90045-4)
- Alberti, G., Zimmet, P., Shaw, J., Bloomgarden, Z., Kaufman, F., & Silink, M. (2004). Type 2 diabetes in the young: The evolving epidemic. The international diabetes federation consensus workshop. *Diabetes care*, 27, 1798-1811. doi: 10.2337/diacare.27.7.1798
- Anderson, A. B. (2005). *Socio-demographic study of Aboriginal population in Saskatoon*. Bridges and Foundations Project on Urban Aboriginal Housing, University of Saskatchewan. Retrieved from
http://www.bridgesandfoundations.usask.ca/reports/sociodemo_reportfinal.pdf
- Anderson, K. (2005). Minobimadziwin: The good life for Aboriginal women. *Centres of Excellence for Women's Health Research Bulletin: Envisioning Healthy Living for Women*, 4, 8-9. Retrieved from <http://www.cewh-cesf.ca/en/publications/RB/v4n2/page4.shtml>
- Appel L. J., Miller, E. R., Seidler, A. J., & Whelton, P. K. (1993). Does supplementation of diet with 'fish oil' reduce blood pressure? A meta-analysis of controlled clinical trials. *Archives of Internal Medicine*, 153, 1429-1438. [doi:10.1001/archinte.153.12.1429](https://doi.org/10.1001/archinte.153.12.1429)

- Arnold, O. F. & Bruce, A. (2005). Nursing practice with Aboriginal communities: Expanding worldviews. *Nursing Science Quarterly*, 18, 259-263. Doi: 10.1177/0894318405277632.
- Baker, S. E. & Edwards, R. (nd). *National Centre for Research Methods Review Paper: How many qualitative interviews is enough?* Retrieved from http://eprints.ncrm.ac.uk/2273/4/how_many_interviews.pdf
- Balfour, L., Kowal, J., Silverman, A., Tasca, G. A., Angel, J. B., Macpherson, P. A., ...Cameron, D. W (2006). A randomized controlled psycho-education intervention trial: Improving psychological readiness for successful HIV medication adherence and reducing depression before initiating HAART. *AIDS Care*, 18, 830-838. [doi:10.1080/09540120500466820](https://doi.org/10.1080/09540120500466820)
- Bandura, A. (1986). *Social foundations of thought and action: A social cognitive theory*. Englewood, NJ: Prentice Hall.
- Barlow, M. & Clarke, T. (2002, Sept. 2). Who owns water? *The Nation*. Retrieved from <http://lege.net/blog.lege.net/ratical.org/co-globalize/whoOwnsWater.pdf>
- Barnsley, J. & Ellis, D. (1992). *Research for change: Participatory action research for community groups*. Vancouver, B.C.: The Women's Research Center.
- Beevers, G., Lip, G. Y. H., & O'Brien, E. (2001). ABC of hypertension. The pathophysiology of hypertension. *British Medical Journal*, 322, 912-916. [doi:10.1136/bmj.322.7291.912](https://doi.org/10.1136/bmj.322.7291.912)
- Benoit, C., Jansson, M., Millar, A., & Phillips, R. (2005). Community-academic research on hard-to-reach populations: Benefits and challenges. *Qualitative Health Research*, 15, 263-282. [doi:10.1177/1049732304267752](https://doi.org/10.1177/1049732304267752)
- Billie Littlechild, D., Este, D., Galabuzi, G. E., & Basse Etowa, J. (2011). Racism as a

determinant of health. *Canadian Race Relations Foundation. Best Practice Reader.*

Retrieved from <http://www.crr.ca/content/view/334/551/lang.english>

Blackstock, C., Trocmé, N., & Bennett, M. (2004). Child maltreatment investigations among Aboriginal and non-Aboriginal families in Canada. *Violence Against Women, 10*, 901-916. [doi:10.1177/1077801204266312](https://doi.org/10.1177/1077801204266312)

Blatchford, C. (2001). *Christie Blatchford in Hobbema: Where does the money go?* The National Post. Retrieved from <http://fullcomment.nationalpost.com/2011/07/16/christie-blatchford-in-hobbema-where-does-the-money-go/>

Bosworth, H. B., Bartash, R. M., Olsen, M. K., Steffens, D. C. (2003). The association of psychosocial factors and depression with hypertension in older adults. *International Journal of Geriatric Psychiatry, 18*, 1142-1148. [doi:10.1002/gps.1026](https://doi.org/10.1002/gps.1026)

Bosworth, H. B., Powers, B., Grubber, J. M., Thorpe, C. T., Olsen, M. K., Orr, M., & Oddone, E. (2008). Ethnic differences in blood pressure control: Potential explanatory factors. *Journal General Internal Medicine, 23*, 692-698. Doi: 10.1007/s11606-008-0547-7.

Boutin-Foster, C., Ravenell, J. E., Greenfield, V. W., Medmim, B., & Ogedegbe, G. (2009). Applying qualitative methods in developing a culturally tailored workbook for Black patients with hypertension. *Patient Education and Counseling, 77*, 144-147.

[doi:10.1016/j.pec.2009.03.008](https://doi.org/10.1016/j.pec.2009.03.008)

Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*, 77-101. [doi:10.1191/1478088706qp063oa](https://doi.org/10.1191/1478088706qp063oa)

Browne, A. J. & Varcoe, C. (2006). Critical cultural perspectives and health care involving Aboriginal peoples. *Contemporary Nurse, 22*, 155-167. [doi:10.5172/conu.2006.22.2.155](https://doi.org/10.5172/conu.2006.22.2.155)

Bryant, L.D., Bown, N., Bekker, H.L., & House, A. (2007). The lure of 'patient choice.' *British*

- Journal of General Practice*, 57, 822-826. Retrieved from <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2151816/>
- Burr, V. (1995). *An introduction to social constructionism*. London, UK: Routledge.
- Calverley, K. (2009). *Challenging the dominant biomedical discourses for hypertension in Canadian Aboriginal Peoples*. Paper presented at the International Society for Critical Health Psychology Conference, Lausanne, Switzerland.
- Calverley, K. (2012). Hypertension affecting the Aboriginal community at higher rates. *Indigenous Times*, 2, Vol. 17, 12. Saskatoon, SK.
- Campbell, C. (2004). Health psychology and community action. In M. Murray (Eds.), *Critical health psychology* (pp. 203-221). Hampshire, UK: Palgrave MacMillan.
- Campbell, N. R., Petrella, R., & Kaczorowski, J. (2006). Public education on hypertension: A new initiative to improve the prevention and control of hypertension in Canada. *Canadian Journal of Cardiology*, 22, 599-603. [doi:10.1016/S0828-282X\(06\)70282-3](https://doi.org/10.1016/S0828-282X(06)70282-3)
- Campbell, N. R., Gilbert, R. E., Leiter, L. A., Laroche, P., Tobe, S., Chockalingarn, A., ...Harris, S. (2012). Hypertension revisited. *Canadian Family Physician*, 58, 634-636.
- Canadian Broadcasting Corporation. (2004). *My big fat diet*. Retrieved August 19, 2010 from <http://www.cbc.ca/thelens/bigfatdiet/>
- Canadian Hypertension Education Program. (2012). *The 2012 CHEP recommendations*. Retrieved from <http://www.hypertension.ca/chep-recommendations>.
- Canadian Hypertension Society. (2011). *What is hypertension?* Retrieved from <http://www.hypertension.ca/what-is-hypertension-dp1>
- Canadian Institute for Health Information. (2004). *Improving the health of Canadians:*

Aboriginal Peoples' health. Report retrieved from

http://secure.cihi.ca/cihiweb/products/IHC2004_ch4_e.pdf

Canadian Institute for Health Information. (2010). *Health care spending to reach \$192 billion this year*. Retrieved from http://www.cihi.ca/CIHI-ext-portal/internet/en/Document/spending+and+health+workforce/spending/RELEASE_28OCT10

Canadian Institutes of Health Research. (2007). *CIHR guidelines for health research involving Aboriginal people*. Retrieved November 10, 2007 from http://www.cihr-irsc.gc.ca/e/documents/ethics_aboriginal_guidelines_e.pdf

Canadian Medicine News. (2009, April 23). *Investigate "institutional racism" in healthcare: Indigenous MD's*. Retrieved from <http://www.canadianmedicineneews.com/2009/04/investigate-institutional-racism-in.html>

Canadian Mortgage and Housing Association (nd). *Affordable housing*. Retrieved on March 12, 2012 from http://www.cmhc-schl.gc.ca/en/corp/faq/faq_002.cfm#4

Canadian Psychological Association. (2000). *Strengthening primary care. The contribution of the science and practice of psychology*. Ottawa: ON, CPA.

Centre for Aboriginal Health Research. (2009). *Indigenous water ways*. Community-Based Research Workshop Series on the Social Contexts of Safe Drinking Water. Retrieved from <http://cahr.uvic.ca/programs-research/programs/community-based-research/>

Child Hunger Education Program. (nd). Retrieved on March 28, 2012 from http://www.chep.org/cg/cg_brochure.pdf

Chobanian, A. V., Bakris, G. L., Black, W. C., Cushman, L. A., Green, L. E., Izzo, J. L.,

- ...National High Blood Pressure Education Program Coordinating Committee (2003). The seventh report on the Joint National Committee on prevention, detection, evaluation, and treatment of high blood pressure. *Journal of the American Medical Association*, 289, 2560-2571. [doi:10.1001/jama.289.19.2560](https://doi.org/10.1001/jama.289.19.2560)
- Cohen, D., McCubbin, M., Collin, J., & Perodeau, G. (2001). Medications as social phenomena. *Health*, 5, 441-469. [doi:10.1177/136345930100500403](https://doi.org/10.1177/136345930100500403)
- Cohen, S. (2004). Social relationships and health. *American Psychologist*, 59, 676-84. [doi:10.1037/0003-066X.59.8.676](https://doi.org/10.1037/0003-066X.59.8.676)
- Conrad, P. (1994) Wellness as virtue: Morality & the pursuit of health. *Culture, Medicine, and Psychiatry*, 18, 385-401. [doi:10.1007/BF01379232](https://doi.org/10.1007/BF01379232)
- Cook, C. (2007). Models to evaluate patient compliance. In J. E. Fincham (Eds.), *Patient compliance with medications: Issues and opportunities* (pp.89-114). New York: Hawthorn Press Inc.
- Crawford, R. (1998). You are dangerous to your health: The ideology and politics of victim blaming. In L. Mackay, K. Sothill, & K. M. Melia (Eds.), *Classic texts in health care*. (pp. 84-89). Oxford, UK: Reed Educational and Professional Publishing.
- Crawford, R. (2006). Health as a meaningful social practice. *Health*, 10, 401-420. [doi:10.1177/1363459306067310](https://doi.org/10.1177/1363459306067310)
- Crossley, M. L. (2001a). Rethinking psychological approaches towards health promotion. *Psychology and Health*, 16, 161-177. [doi:10.1080/08870440108405497](https://doi.org/10.1080/08870440108405497)
- Crossley, M. L. (2001b). Do we need to rethink health psychology? *Psychology, Health, & Medicine*, 6 (3), 243-255. [doi:10.1080/13548500120053364](https://doi.org/10.1080/13548500120053364)
- Crossley, M. (2002). "Could you please pass one of those health leaflets along?"

- Exploring health, morality, and resistance through focus groups. *Social Science and Medicine*, 55, 1471-1483. [doi:10.1016/S0277-9536\(01\)00265-9](https://doi.org/10.1016/S0277-9536(01)00265-9)
- Crossley, M. (2003). "Would you consider yourself a healthy person?" Using focus groups to explore health as a moral phenomenon. *Journal of Health Psychology*, 8, 501-514. [doi:10.1177/13591053030085003](https://doi.org/10.1177/13591053030085003)
- Crotty, M. (1998). *The foundations of social research: Meaning and perspective in the research process*. London, UK: Sage Publications Ltd.
- Daniel, H. I., & Rotimi, C. N. (2003). Genetic epidemiology of hypertension: An update on the African diaspora. *Ethnicity & Disease*, 13, 53-66.
- Davidson, K., MacGregor, M. W., Stuhr, J., & Gidron, Y. (1999). Increasing constructive anger verbal behaviour decreases resting blood pressure: A secondary analysis of a randomized controlled intervention. *International Journal of Behavioural Medicine*, 6, 268-278. [doi:10.1207/s15327558ijbm0603_5](https://doi.org/10.1207/s15327558ijbm0603_5)
- Dawber, T. R. (1980). *The Framingham study: The epidemiology of atherosclerotic disease*. Cambridge, MA: Harvard University Press.
- Degrandpre, R. J. (2000). *Ritalin nation*. New York, NY: WW Norton & Company Inc.
- Denzin, N. K. & Lincoln, Y. S. (2008). Introduction: Critical methodology and Indigenous inquiry. In N.K. Denzin, Y.S. Lincoln, & L.T. Smith (Eds.), *Handbook of critical and indigenous methodologies* (pp. 1-17). Thousand Oaks, CA: Sage Publications Ltd.
- Denzin, N. K., Lincoln, Y. S. & Smith, L.T. (Eds.) (2008). *Handbook of critical and indigenous methodologies*. Thousand Oaks, CA: Sage Publications Ltd.
- Dickson, G. (1997). *Participatory action research and health promotion: The grandmothers'*

- story* (Doctoral dissertation). Retrieved from ProQuest Dissertations & Theses (PQDT).
Accension or order no. NQ24012. Retrieved from
<http://search.proquest.com.cyber.usask.ca/pqdtft/docview/304397037/abstract/1381A8920E31434E9D7/4?accountid=14739>
- DiMatteo, M. R. (2004). Social support and patient adherence to medical treatment: A meta analysis. *Health Psychology, 23*, 207-218. [doi:10.1037/0278-6133.23.2.207](https://doi.org/10.1037/0278-6133.23.2.207)
- Echenberg, M. (2002). Petis redux: The initial years of the third bubonic plague pandemic, 1894-1901. *Journal of World History, 13*, 429-449. [doi:10.1353/jwh.2002.0033](https://doi.org/10.1353/jwh.2002.0033)
- Edgar, A. (2006). *Habermas: The key concepts*. New York, NY: Routledge.
- Elliot, C. T., & de Leeuw, S. N. (2009). Our aboriginal relations: When family doctors and Aboriginal patients meet. *Canadian Family Physician, 55*(4), 443-444. Retrieved from
<http://www.ncbi.nlm.nih.gov.cyber.usask.ca/pmc/articles/PMC2669016/pdf/0550443.pdf>
- Environics Institute. (2011). *Urban Aboriginal peoples study: Saskatoon report*. Toronto, Canada: Interprovincial Group. Retrieved from <http://uaps.ca/wp-content/uploads/2010/02/UAPS-Saskatoon-report.pdf>
- Evans, M., Hole, R., Berg, L., Hutchinson, P. & Sookraj, D. (2009). Common insights, differing methodologies: Towards a fusion of Indigenous methodologies, participatory action research and white studies in an urban Aboriginal research agenda. *Qualitative Inquiry, 15*, 893-910. [doi:10.1177/1077800409333392](https://doi.org/10.1177/1077800409333392)
- Fals-Borda, O. & Rahman, M. A. (1991). *Action and knowledge. Breaking the monopoly with participatory action research*. London, UK: Intermediate Technology Publications.
- First Nations Centre. (1999). *First Nations and Inuit regional health survey*. First Nations and

- Inuit Regional Health Survey National Steering Committee. Retrieved from http://www.rhs-ers.ca/sites/default/files/ENpdf/RHS_1997/rhs_1997_final_report.pdf
- First Nations Centre. (2006). *First Nations regional longitudinal health survey (RHS): The peoples' report*. Ottawa, ON: Assembly of First Nations. Retrieved from http://www.rhs-ers.ca/sites/default/files/ENpdf/RHS_2002/rhs2002-03-the_peoples_report_afn.pdf
- Foucault, M. (1980). *Power/Knowledge: Selected interviews and other writings 1972-1977*. New York, NY: Pantheon.
- Freire, P. (2001). *Pedagogy of the oppressed*. New York, NY: Continuum.
- Garro, L. C. (1998). Explaining high blood pressure: Variation in knowledge about illness. *American Ethnologist*, 15, 98-199. [doi:10.1525/ae.1988.15.1.02a00070](https://doi.org/10.1525/ae.1988.15.1.02a00070)
- Garro, L. C. (1995). Individual or societal responsibility? Explanations of diabetes in an Anishinaabe (Ojibway) community. *Social Science Medicine*, 40, 37-46. [doi:10.1016/0277-9536\(94\)00125-D](https://doi.org/10.1016/0277-9536(94)00125-D)
- Gibson, N., Gibson, G., & Macaulay, A. C. (2001). Community-based research: Negotiating research agendas and evaluating outcomes. In J. M. Morse, J. M. Swanson, & A. J. Kuzel (Eds.), *The Nature of qualitative evidence* (pp.161-182). Thousand Oaks, CA: Sage Publications Ltd.
- Grant, R. W., Singer, D. E., & Meigs, J.B. (2005). Medication adherence before an increase in antihypertensive therapy: A cohort study using pharmacy claims data. *Clinical Therapeutics*, 27, 773-781. [doi:10.1016/j.clinthera.2005.06.004](https://doi.org/10.1016/j.clinthera.2005.06.004)
- Green, L. W. & Glasgow, R. E. (2006). Evaluating the relevance, generalization, and

- applicability of research. Issues in external validation and translation methodology. *Evaluation & the Health Professions*, 29, 126-153. [doi:10.1177/0163278705284445](https://doi.org/10.1177/0163278705284445)
- Gustafson, D. L. & Reitmanova, S. (2010). How are we 'doing' cultural diversity? A look across English Canadian undergraduate medical school programmes. *Medical Teacher*, 32, 816-823. [doi:10.3109/01421590903394595](https://doi.org/10.3109/01421590903394595)
- Hamil, S. & Dickey, M. (2005). Cultural competence: What is needed in working with Native Americans with HIV/AIDS? *Journal of the Association of Nurses in AIDS Care*, 16, 64-69. [doi:10.1016/j.jana.2005.05.007](https://doi.org/10.1016/j.jana.2005.05.007)
- Hammond, D., Fong, G. T., Borland, R., Cummings, M., McNeill, A., & Driesen, P. (2007). Texts and graphic warning on cigarette packages: Findings from the international tobacco control four country study. *American Journal of Preventive Medicine*, 32, 202-209. Doi: 10.1016/j.amepre.2006.11.011
- Hammond, D., Fong, G. T., McDonald, P. W., Cameron, R., & Brown, S. (2003). The impact of the graphic Canadian warning labels on adult smoking. *Tobacco control*, 12, 391-395. [doi:10.1136/tc.12.4.391](https://doi.org/10.1136/tc.12.4.391)
- Hammond, D., Fong, G. T., McDonald, P. W., Brown, S., & Cameron, R. (2006). Showing leads to doing: Graphic cigarette warning labels are an effective public health policy. *European Journal of Public Health*, 16, 223-224. [doi:10.1093/eurpub/ckl037](https://doi.org/10.1093/eurpub/ckl037)
- Hardey, M. (1999). Doctor in the house: The internet as a source of lay knowledge and the challenge to expertise. *Sociology of Health & Illness*, 21, 820-835. [doi:10.1111/1467-9566.00185](https://doi.org/10.1111/1467-9566.00185)
- Haverkamp, B. E. & Young, R. A. (2007). Paradigms, purpose, and the role of the literature:

Formulating a rationale for qualitative investigations. *The Counselling Psychologist*, 35, 265-294. [doi:10.1177/0011000006292597](https://doi.org/10.1177/0011000006292597)

Health Canada. (1998). *Economic burden of illness*. Report retrieved from

<http://www.phac-aspc.gc.ca/publicat/ebic-femc98/pdf/ebic1998.pdf>

Health Canada. (2000) *Facts and issues: The health of Aboriginal women*. Report retrieved from

http://www.hc-sc.gc.ca/women/english/facts_aborig.htm

Health Canada. (2006). *First Nations & Inuit health*. Report retrieved from

http://hc-sc.gc.ca/fnih-spni/diseases-maladies/index_e.html

Heart and Stroke Foundation of Canada. (n.d.). *Taking control: Lower your risk of heart disease and stroke. A guide for Aboriginal Peoples*. Report retrieved from

http://www.heartandstroke.com/atf/cf/%7B99452D8B-E7F1-4BD6-A57D-B136CE6C95BF%7D/Aboriginal_TakingControl.pdf

Heart and Stroke Foundation of Canada. (1999). *The changing face of heart and stroke*

in Canada 2000. Report retrieved from <http://www.phac-aspc.gc.ca/ccdpc-cpcmc/cvd-mcv/publications/pdf/card2ke.pdf>

Heart and Stroke Foundation of Canada. (2002). *Women: Heart disease and stroke*. Report retrieved from

http://ww2.heartandstroke.ca/Page.asp?PageID=1562&ArticleID=1362&Src=&From=SubCategory#why_important_to_treat

Heart and Stroke Foundation of Canada. (2003). *The growing burden of heart disease and stroke in Canada in 2003*. Report retrieved from

http://www.cvdinfobase.ca/cvdbook/CVD_En03.pdf

Heart and Stroke Foundation of Canada. (2006). *Tipping the scales of progress: Heart disease*

and stroke in Canada 2006. Report retrieved from

http://www.heartandstroke.com/atf/cf/%7B99452D8B-E7F1-4BD6-A57D-B136CE6C95BF%7D/Tipping_the_Scales_new.pdf

Heart and Stroke Foundation of Canada. (2010). *Heart and Stroke Foundation research report*.

Report retrieved from

http://hsf.ca/research/sites/default/files/HSFC_ResearchReport%20_Eng_2009-2010.pdf

Heart and Stroke Foundation of Canada. (2011a). *High blood pressure*. Report retrieved from

http://www.heartandstroke.mb.ca/site/c.lgLSIV0yGpF/b.3661255/k.EE9/Stroke_High_blood_pressure_hypertension.htm

Heart and Stroke Foundation of Canada. (2011b). *Insight: Heart and Stroke Foundation*

Research newsletter 2011-2012. Report retrieved from

http://hsf.ca/research/sites/default/files/HSFC_InSight2011E.pdf

Herlihy, D. (1997). *The Black Death and the transformation of the west*. Cambridge, MA:

Harvard University Press.

Herr, K. & Anderson, G. L. (2005). *The action research dissertation: A guide for students and faculty*. Thousand Oaks, CA: Sage Publications Ltd.

Hill, M. N., Bone, L. R., Kim, M. T., Miller, D. J., Dennison, C. R., & Levine, D. M. (1999).

Barriers to hypertension care and control in young urban black men. *American Journal of Hypertension*, 12, 951-958. [doi:10.1016/S0895-7061\(99\)00121-1](https://doi.org/10.1016/S0895-7061(99)00121-1)

Hong, T.B., Oddone, E. Z., Dudley, T. K. & Bosworth, H. D. (2006). Medication barriers

and anti-hypertensive medication adherence: The moderating role of locus of control.

Psychology, Health & Medicine, 11, 20-28. [doi:10.1080/14786430500228580](https://doi.org/10.1080/14786430500228580)

Horowitz, C. R., Tuzzio, L., Rojas, M., Monteith, S. A. & Sisk, J. E. (2004). How do urban

- African Americans and Latinos view the influence of diet on hypertension? *Journal of Health Care for the Poor and Underserved*, 15, 631-644. [doi:10.1353/hpu.2004.0061](https://doi.org/10.1353/hpu.2004.0061)
- Howard, B. V., Lee, E. T., Cowan, L. D., Devereux, R. B., Galloway, J. M., Go, O. T., ... Welty, T. K. (1999). Rising tide of cardiovascular disease in American Indians: The Strong Heart study. *Circulation*, 99, 2389-2395. doi: 10.1161/01.CIR.99.18.2389
- Hunter, L. M., Logan, J., Goulet, J. G., Barton, S. (2006). Aboriginal healing: Regaining balance and culture. *Journal of Transcultural Nursing*, 17, 13-22.
[doi:10.1177/1043659605278937](https://doi.org/10.1177/1043659605278937)
- Ibrahim, S. A. (2003). Hypertension and medication adherence among African Americans: A potential factor in cardiovascular disease. *E-Journal of the National Medical Association*, 95, 28-29. Retrieved from
<http://www.ncbi.nlm.nih.gov/cyber.usask.ca/pmc/articles/PMC2594369/pdf/jnma00305-0054.pdf>
- Indigenous Peoples Health Research Centre. (2004). *Community based projects 2004*. Retrieved on March 26, 2012 from
http://iphrc.ca/researchers_communities/project_summaries/2004#Bridging_the_Gap_Between_Environmental_Contaminants_and_Health
- Indigenous Peoples Health Research Centre. (2004). *The ethics of research involving Indigenous peoples*. Report retrieved on June 8, 2008 from
http://www.iphrc.ca/documents/ethics_review_iphrc.pdf
- Indigenous Peoples Health Research Centre. (2006). *Miyo-Mahcihowin: A report on Indigenous health in Saskatchewan*. Report retrieved June 8, 2008 from
<http://www.iphrc.ca/resources/Miyo-Mahcihowin.pdf>

- Institute for Aboriginal Peoples' Health. (2012). Traditional ways of knowing about health research to reduce health inequities in First Nations, Inuit, and Métis. *Aboriginal Health Research News, 1*, 1-2.
- Joffres, M. R., Campbell, N. R. C., Manns, B. & Tu, K. (2007). Estimate of the benefits of a population based reduction in dietary sodium additives on hypertension and its related health care costs in Canada. *Canadian Journal of Cardiology, 23*, 437- 443.
[doi:10.1016/S0828-282X\(07\)70780-8](https://doi.org/10.1016/S0828-282X(07)70780-8)
- Johnson, A. P. (2005). *A short guide to action research, 2nd Edition*. Boston, MA: Pearson Education Inc.
- Johnson, M. J. (2002). The medication adherence model: A guide for assessing medication taking. *Research and Theory for Nursing Practice: An International Journal, 16*, 179-192. [doi:10.1891/rtnp.16.3.179.53008](https://doi.org/10.1891/rtnp.16.3.179.53008)
- Jonas, B. S. & Lando, J. F. (2000). Negative affect as a prospective risk factor for hypertension. *E-Psychosomatic Medicine, 62*(2), 188-196. Retrieved from http://ovidsp.tx.ovid.com.cyber.usask.ca/sp-3.5.1a/ovidweb.cgi?&S=CPMOFPFEHJDDAIOCNCALLEEIBCEKNAA00&Link+Set=S.sh.15.16.20.24%7c6%7csl_10
- Kaplan, M. S., Chang, C., Newsom, J. T., & McFarland, B. H. (2002). Acculturation status and hypertension among Asian immigrants in Canada. *Journal of Epidemiology and Community Health, 56*, 455-456. [doi:10.1136/jech.56.6.455](https://doi.org/10.1136/jech.56.6.455)
- Karnieli-Miller, O. & Eisikovits, K. (2009). Physician as partner or salesman? Shared decision-making in real time encounters. *Social Science & Medicine, 69*, 1-8.
[doi:10.1016/j.socscimed.2009.04.030](https://doi.org/10.1016/j.socscimed.2009.04.030)

- Karppanen, H. & Mervaala, E. (2006). Sodium intake and hypertension. *Progress in Cardiovascular Diseases*, 49, 59-75. Doi: 10.1016/j.pcad.2006.07.001.
- Kelly, L. & Brown, J. B. (2002). Listening to Native patients. Changes in physician's understanding and behaviour. *Canadian Family Physician*, 48, 1645-1652 Retrieved from <http://www.ncbi.nlm.nih.gov.cyber.usask.ca/pmc/articles/PMC2213949/pdf/12449549.pdf>
- Kershaw, K. (2010). *The geographic context and black-white disparities in hypertension* (Doctoral dissertation). Retrieved from ProQuest Dissertations & Theses (PQDT). Accension or order no. Retrieved from <http://search.proquest.com/docview/851184731?accountid=14739>.
- Kim, M. T., Kim, K. B., Juon, H. S., & Hill, M. N. (2000). Prevalence and factors associated with high blood pressure in Korean Americans. *Ethnicity and Disease*, 10(3), 364-374. Retrieved from <http://ukpmc.ac.uk/abstract/MED/11110353/reload=0;jsessionid=akySULKQPhEz9Zb9pNYO.136>
- King, M., Smith, A., & Gracey, M. (2009). Indigenous health part 2: The underlying causes of the health gap. *Lancet*, 374, 76–85 [doi:10.1016/S0140-6736\(09\)60827-8](https://doi.org/10.1016/S0140-6736(09)60827-8)
- Kinsella, W. J. (2002). Problematizing the distinction between expert and lay knowledge. *The New Jersey Journal of Communication*, 10, 191-207. [doi:10.1080/15456870209367428](https://doi.org/10.1080/15456870209367428)
- Kirkpatrick, S. & Tarasuk, V. (2003). The relationship between low income and household food expenditure patterns in Canada. *Public Health Nutrition*, 6, 589-597. [doi:10.1079/PHN2003517](https://doi.org/10.1079/PHN2003517)
- Kleinman, D. L. (1998). Beyond the science wars: Contemplating the democratization of

- science. *Politics and the Life Sciences*, 16(2), 133-145. Retrieved by <http://www.jstor.org/stable/4236431>
- Koch, T., Jenkin, P. & Kralik, D. (2004). Chronic illness self-management: Locating the 'self.' *Journal of Advanced Nursing*, 48, 484-492. [doi:10.1111/j.1365-2648.2004.03237.x](https://doi.org/10.1111/j.1365-2648.2004.03237.x)
- Kuhnlein, H. V. & Receveur, O. (1996). Dietary change and traditional food systems of Indigenous peoples. *Annual Review of Nutrition*, 16, 417-442. [doi:10.1146/annurev.nutr.16.1.417](https://doi.org/10.1146/annurev.nutr.16.1.417)
- Lalonde, M. (1974). A new perspective on the health of Canadians. A working document. Ottawa: Government of Canada. Retrieved from http://www.hc-sc.gc.ca/hcs-sss/alt_formats/hpb-dgps/pdf/pubs/1974-lalonde/lalonde-eng.pdf
- Lather, P. (2007). Critical pedagogy and its complicities: A praxis of stuck places. *Educational theory*, 48, 487-497. [doi:10.1111/j.1741-5446.1998.00487.x](https://doi.org/10.1111/j.1741-5446.1998.00487.x)
- LaVeist, T. A. (2005). Disentangling race and socioeconomic status: A key to understanding health inequalities. *Journal of Urban Health: Bulletin of the New York Academy of Medicine*, 82, 26-34. [doi:10.1093/jurban/jti061](https://doi.org/10.1093/jurban/jti061)
- Lemstra, M. & Neudorf, C. (2008a) *Health disparity in Saskatoon: Analysis to intervention*. Saskatoon, SK: Saskatoon Health Region. http://www.saskatoonhealthregion.ca/your_health/documents/PHO/HealthDisparityRept-complete.pdf
- Lemstra, M. & Neudorf, C. (2008b) *Health disparity in Saskatoon: Analysis to intervention*. Summary. Saskatoon, SK: Saskatoon Health Region. http://www.saskatoonhealthregion.ca/your_health/documents/PHO/HealthDisparityRept-complete.pdf

- Lemstra, M., Neudorf, C., & Opondo, J. (2006). Health disparity by neighbourhood income. *Canadian Journal of Public Health*, 97(6), 435-439. Retrieved from <http://web.ebscohost.com.cyber.usask.ca/ehost/pdfviewer/pdfviewer?vid=3&hid=18&sid=e830531c-6560-4d83-80c7-97db94c516b9%40sessionmgr15>
- Li, W., Wallhagen, M. I., & Froelicher, E. S. (2007). Hypertension control, predictors for medication adherence and gender differences in older Chinese immigrants. *Journal of Advanced Nursing*, 61, 326-335. [doi:10.1111/j.1365-2648.2007.04537.x](https://doi.org/10.1111/j.1365-2648.2007.04537.x)
- Lidskog, R. (2008). Scientised citizens and democratised science: Re-assessing the expert-lay divide. *Journal of Risk Research*, 11, 69-86. [doi:10.1080/13669870701521636](https://doi.org/10.1080/13669870701521636)
- Loe, M. (2006). *The rise of Viagra: How the little blue pill changed sex in America*. New York, NY: New York University Press.
- Mancia, G., De Backer, G., Dominiczak, A., Cifkova, R., Fagard, R., Germano, G., ... Zanchetti, A. (2007). 2007 Guidelines for the management of arterial hypertension. The Task Force for the Management of Arterial Hypertension of the European Society of Hypertension (ESH) and of the European Society of Cardiology (ESC). Retrieved from <http://www.seh-lelha.org/pdf/guia2007seh.pdf>
- Manitoba Centre for Health Policy. (2010). *Growing gaps in wealth and health for Manitobans*. Report retrieved from http://mchp-appserv.cpe.umanitoba.ca/reference/MCHP-Health_Ineq_summary_final_WEB.pdf
- Marin, G., Burhransstipanov, L., Connell, C. M., Gielen, A. C., Helizter, A., Lorig, K., ... Thomas, S. (1994). A research agenda for health education among underserved populations. *Health Education & Behavior*, 22, 346-363. [doi:10.1177/109019819402200307](https://doi.org/10.1177/109019819402200307)

Marmot, M. (2005). Social determinants in health inequalities. *The Lancet*, 365, 1099-1104.

[doi:10.1016/S0140-6736\(05\)71146-6](https://doi.org/10.1016/S0140-6736(05)71146-6)

Masad, P. S., Roca, M., Turner, M. S., & Kane, J. M. (2009). Partial adherence to antipsychotic medication impacts the course of illness in patients with schizophrenia: A review.

Primary Care Companion Journal of Clinical Psychiatry, 11, 147-154. Doi: 10.

4088/PCC.08r00612

Mazor, K. M., Fischer, M. A., & Billings-Gagliardi, S. (2008). Initial acceptance of treatment with antihypertensive medication: The importance of communication, trust, and beliefs.

Journal of Communication in Healthcare, 1, 311-323. [doi:10.1179/175380608790912978](https://doi.org/10.1179/175380608790912978)

McAuley, E., Lox, C., & Duncan, T. E. (1993). Long-term maintenance of exercise, self-efficacy, and physiological change in older adults. *Journal of Gerontology:*

PSYCHOLOGICAL SCIENCES, 48, 218-224. doi: 10.1093/geronj/48.4.P218

McKinlay, J. B. (1998). Paradigmatic obstacles to improving the health of populations – Implications for health policy. *Salud Publica de Mexico*, 40, 369-379.

[doi:10.1590/S0036-36341998000400010](https://doi.org/10.1590/S0036-36341998000400010)

Meichenbaum, D. & Turk, D. C. (1987). *Facilitating treatment adherence: A practitioner's guidebook*. New York, NY: Plenum Press.

Meyer, J. (2006). Action research. In C. Pope & N. Mays (Eds.), *Qualitative research in health care* (pp.121-131). Thousand Oaks, CA: Sage Publications Ltd.

Mikkonen, J., & Raphael, D. (2010). *Social determinants of health: The Canadian facts*.

Toronto: York University School of Health Policy and Management

Mills, P. J., Davidson, K., W., & Farag, N. H. (2004). Work stress and hypertension: A call from

research into intervention. *Annals of Behavioural Medicine*, 28, 1-3.

Doi:10.1207/s15324796abm2801_1

Mohan, Campbell, & Willis. (2009). Effective population-wide public health interventions to promote sodium reduction. *Canadian Medical Association Journal*, 181, 605-609.

[doi:10.1503/cmaj.090361](https://doi.org/10.1503/cmaj.090361)

Mol, A. (2008). *The logic of care: Health and the problem of patient choice*. Abingdon, Oxon: Routledge.

Morley, P. (1987). Culture and the cognitive world of traditional medical beliefs: Some preliminary considerations. In P. Morley & R. Wallis (Eds.), *Culture and curing: Anthropological perspectives on traditional medical beliefs and practices* (pp. 3-12). Pittsburgh, PA: University of Pittsburgh Press.

Morris M. C., Sacks F, Rosner B. (1993). Does fish oil lower blood pressure? A meta-analysis of controlled trials. *Circulation*, 88, 523–533. Doi: 10.1161/01.CIR.88.2.523

Morrow, R.A. & Brown, D. D. (1994). *Critical theory and methodology, Volume 3*. Thousand Oaks, CA: Sage.

Murray, M. (Eds.) (2004). *Critical health psychology*. Hampshire, UK: Palgrave MacMillan.

Mussell, W. J. (2006). *Restoration of well-being for Canada's First Peoples*. Retrieved from

<http://www.caot.ca/pdfs/PaperfAbMentalHealth.pdf>

Nagai, M., Hoshida, S., & Kario, K. (2010). Hypertension and dementia. *American Journal of Hypertension*, 23, 116–124. [doi:10.1038/ajh.2009.212](https://doi.org/10.1038/ajh.2009.212)

National Aboriginal Health Organization. (2002). *Overview of Inuit health*. Retrieved July 8,

2006 from http://16016.vws.magma.ca/english/pdf/bulletin_jan_2003_eng.pdf

National Aboriginal Health Organization. (2003). *Analysis of Aboriginal health careers*.

- Education and training opportunities*. Retrieved July 20, 2011 from http://www.naho.ca/documents/naho/english/pdf/analysis_health_careers.pdf
- National Aboriginal Health Organization. (2006). *Broader determinants of health in an Aboriginal context*. Retrieved June 16, 2009 from http://www.naho.ca/english/pdf/2006_Broader_Determinants.pdf
- National Aboriginal Health Organization. (2007). *OACAP: Ownership, control, access, and possession*. Retrieved June 8, 2008 from http://www.naho.ca/firstnations/english/documents/FNC-OACAP_000.pdf
- National Aboriginal Health Organization. (2008). *Urban First Nations health research discussion paper*. Retrieved August 18, 2010 from <http://www.naho.ca/english/publications.php>
- National Health Service. (2010). *The Expert Patient Programme – What is an Expert Patient?* Retrieved September 16, 2011 from www.nhs.uk/Conditions/Expert-patients-programme-/Pages/Whatisanexpertpatient.aspx
- Nesbitt, S. D. (2005). Hypertension in Black patients: Special issues and considerations. *Current Hypertension Reports*, 7, 244-248. [doi:10.1007/s11906-005-0020-5](https://doi.org/10.1007/s11906-005-0020-5)
- Newbold, K. B. (1998). Problems in search of solutions: Health and Canadian Aboriginals. *Journal of Community Health*, 23(1), 59-73. Retrieved from <http://www.springerlink.com.cyber.usask.ca/content/um08365880k5842h/fulltext.pdf>
- Ngoundo Mbongue, T. B., Sommet, A., Pathak, A., & Montastruc, J. L. (2005). “Medicamentation” of society, non-diseases, and non-medications: a point of view from social pharmacology. *European Journal of Clinical Pharmacology*, 61, 309-311. DOI 10.1007/s00228-005-0925-6

- Park, P. (1993). What is participatory research? A theoretical and methodological perspective. In P. Park, M. Brydon-Miller, B. Hall, & T. Jackson (Eds.), *Voices of change: Participatory research in the United States and Canada* (pp.1-20). Toronto, ON: OISE Press.
- Parliamentary Information and Research Services. (2000). *Report of the Royal Commission on Aboriginal Peoples*. Ottawa: The Library of Parliament. Retrieved from <http://www.parl.gc.ca/Content/LOP/ResearchPublications/prb9924-e.htm>
- Penz, E. D., Joffres, M. R., & Campbell, N. R. C. (2008). Reducing dietary sodium and decreases in cardiovascular disease in Canada. *Canadian Journal of Cardiology*, 24, 497-501. [doi:10.1016/S0828-282X\(08\)70625-1](https://doi.org/10.1016/S0828-282X(08)70625-1)
- Pickering, T. G. (2007). Stress, inflammation, and hypertension. *The Journal of Clinical Hypertension*, 9, 567-571. [doi:10.1111/j.1524-6175.2007.06301.x](https://doi.org/10.1111/j.1524-6175.2007.06301.x)
- Pickersgill, M. J. & Owen, A. (1992). Mood-states, recall and subjective comprehensibility of medical information in nonpatient volunteers. *Personality and Individual Differences*, 13, 1299-1305. [doi:10.1016/0191-8869\(92\)90172-L](https://doi.org/10.1016/0191-8869(92)90172-L)
- Poonwasie A. & Charter, A. (2001). An Aboriginal worldview of helping: Empowering approaches. *E-Canadian Journal of Counselling*, 35(1), 63-73.
- Prior, L. (2003). Belief, knowledge, and expertise: the emergence of the lay expert in medical sociology. *Sociology of Health & Illness*, 25, 41-57. [doi:10.1111/1467-9566.00339](https://doi.org/10.1111/1467-9566.00339)
- Prochaska, J. O., DiClemente, C. C., & Norcross, J. C. (1992). In search of how people change. Applications to addictive behaviours. *American Psychologist*, 47, 1102-1114. [doi:10.1037//0003-066X.47.9.1102](https://doi.org/10.1037//0003-066X.47.9.1102)
- Public Health Agency of Canada. (1999). *Diabetes in Canada*. Retrieved from http://www.phac-aspc.gc.ca/publicat/dic-dac99/d20_e.html

- Public Health Agency of Canada. (2003a). *Population health: Determinants of health*. Retrieved from <http://www.phac-aspc.gc.ca/ph-sp/phdd/determinants/index.html#determinants>
- Public Health Agency of Canada. (2003b). *What determines health?* Retrieved from <http://www.phac-aspc.gc.ca/ph-sp/determinants/index-eng.php>
- Public Health Agency of Canada. (2004). *Reducing Health Disparities: Roles of the Health Sector: Discussion Paper*. Retrieved from http://www.phac-aspc.gc.ca/ph-sp/disparities/pdf06/disparities_discussion_paper_e.pdf
- Public Health Agency of Canada. (2010). *Report from the Canadian chronic disease surveillance system: Hypertension in Canada 2010*. Retrieved from http://www.phac-aspc.gc.ca/cd-mc/cvd-mcv/ccdss-snsmc-2010/pdf/CCDSS_HTN_Report_FINAL_EN_20100513.pdf
- Radley, A. (1994). *Making sense of illness: The sociology of health and disease*. London, UK: Sage Publications.
- Raphael, D. (2007). *Poverty and policy in Canada: Implications for health and quality of life*. Toronto, ON: Canadian Scholars' Press Inc.
- Raphael, D. (Ed.) (2009). *Social determinants of health: Canadian perspectives, 2nd Edition*. Toronto, ON: Canadian Scholars' Press Inc.
- Reading, J. (2009). *The crisis of chronic disease among Aboriginal peoples: A challenge for public health, population health, and social policy*. University of Victoria, BC: Centre for Aboriginal Health Research.
- Richardson, M.A., Simons-Morton, B., & Annegers, J. F. (1993). Effect of perceived

- barriers on compliance with antihypertensive medication. *Health Education Quarterly*, 20, 489-503. [doi:10.1177/109019819302000409](https://doi.org/10.1177/109019819302000409)
- Rose, G. (1992). *The strategy of preventive medicine*. Oxford, UK: Oxford University Press.
- Rosenstock, I. M. (1974). The health belief model and preventive behaviour. *Health Education Monographs*, 2, 354-386.
- Roumie, C. L., Greevy, R., Wallston, K. A., Elasy, T. A., Kaltenebach, L., Kotter, K., ...Speroff, T. (2011). Patient centered primary care is associated with patient hypertension medication adherence. *Journal of Behavioural Medicine*, 34, 244-253. [doi:10.1007/s10865-010-9304-6](https://doi.org/10.1007/s10865-010-9304-6)
- Royal Commission on Aboriginal Peoples. (1996). *People to people, nation to nation: Highlights from the report of the Royal Commission on Aboriginal Peoples*. Ottawa, ON: Minister of Supply and Services.
- Saguy, A. C. & Riley, K. W. (2005). Weighing both sides: Morality, mortality, and framing contests over obesity. *Journal of Health Politics, Policy, and Law*, 30, 869-921. [doi:10.1215/03616878-30-5-869](https://doi.org/10.1215/03616878-30-5-869)
- Saskatoon Health Region (nd). *Programs and services: LiveWell chronic disease management*. Retrieved from http://www.saskatoonhealthregion.ca/your_health/ps_cdm_about_livewell.htm
- Saxby, B. K., Harrington, F., McKeith, I. G., Wesnes, K., & Ford, G. A. (2003). Effects of hypertension on attention, memory, and executive function in older adults. *Health Psychology*, 22, 587-591. [doi:10.1037/0278-6133.22.6.587](https://doi.org/10.1037/0278-6133.22.6.587)
- Scherwitz, L., & Rugulies, R. (1991). Life-style and hostility. In H. S. Friedman (Eds.), *Hostility, coping, and health*. (pp.77-98). Washington DC: APA.

- Schlomann, P. & Schmitke, J. (2007). Lay beliefs about hypertension: An interpretive synthesis of the qualitative research. *Journal of the American Academy of Nurse Practitioners*, 19, 358-367. [doi:10.1111/j.1745-7599.2007.00238.x](https://doi.org/10.1111/j.1745-7599.2007.00238.x)
- Silverman, D. (2001). *Interpreting qualitative data: Methods for analysing talk, text, and interaction*, 2nd Edition. Thousand Oaks, CA: Sage.
- Silverman, D. (2005). *Doing qualitative research: A practical handbook*. Thousand Oaks, CA: Sage Publications Ltd.
- Sims-Schouten, W. Riley, S. C. E. & Willig, C. (2007). Critical realism in discourse analysis: A presentation of a systematic method of analysis using women's talk of motherhood, childcare, and female employment as an example. *Theory & Psychology*, 17, 101-124. [doi:10.1177/0959354307073153](https://doi.org/10.1177/0959354307073153)
- Sinclair, R. (2011). *The 60's Scoop*. Retrieved from <http://www.originscanada.org/the-stolen-generation/>
- Smith, L. T. (1999) *Decolonizing methodologies: Research and Indigenous people*. Dunedin, New Zealand: University of Otago Press.
- Sonstroem, R. J. (1997). The physical self-system. A mediator of exercise and self-esteem. In K. R. Fox (Eds.), *The physical self: from motivation to well-being* (pp.3-26). Champaign, IL: Human Kinetics.
- Spicer, J., & Chamberlain, K. (1996). Cynical hostility, anger, and resting blood pressure. *Journal of Psychosomatic Research*, 40, 359-368. [doi:10.1016/0022-3999\(95\)00546-3](https://doi.org/10.1016/0022-3999(95)00546-3)
- Stam, H. J. (2004). A sound mind in a sound body: A critical historical analysis of health

- psychology. In M. P. Murray (Eds.), *Critical health psychology*. (pp. 15-30) London, UK: Palgrave/Macmillan.
- Stainton-Rogers, W. (1991). *Explaining health and illness: An exploration of diversity*. London, UK: Harvester Wheatsheaf.
- Statistics Canada. (2001). *Initial findings: Well-being of the non-reserve Aboriginal population*. Aboriginal Peoples Survey 2001. Retrieved from <http://www.statcan.ca/bsolc/english/bsolc?catno=89-589-X&CHROPG=1>
- Statistics Canada. (2006). *Aboriginal Peoples: Census 2006*. Retrieved from <http://www12.statcan.ca/english/census06/release/aboriginal.cfm>
- Statistics Canada. (2009). *Low income cut-offs*. Retrieved from <http://www.statcan.gc.ca/pub/75f0002m/2009002/s2-eng.htm>
- Statistics Canada. (2012). *Bureau of statistics*. Government of Canada. Retrieved from <http://www.stats.gov.sk.ca/>
- Stephens, C. (2009). Racism and inequalities in health: Notes towards an agenda for critical health psychology. *Journal of Health Psychology, 14*, 655-659.
- Stout, M. D., Kipling, G. D., & Stout, R. (2001). *Aboriginal women's health research synthesis project: Final report*. Centres of Excellence for Women's Health Research Synthesis Group. Retrieved from <http://www.cewh-esf.ca/en/resources/synthesis/synthesis-en.pdf>
- Stringer, E. T. (2007). *Action research, 3rd edition*. Thousand Oaks, CA: Sage Publications Ltd.
- Stringer, E. & Genat, W. (2004). *Action research in health*. Upper Saddle River, NJ: Pearson Education Inc.
- Sudano, J. Jr. & Baker, D. W. (2001). Antihypertensive medication use in Hispanic adults: A

comparison with Black adults and White adults. *Medical Care*, 39, 575-587.

[doi:10.1097/00005650-200106000-00006](https://doi.org/10.1097/00005650-200106000-00006)

Suurmond, J. & Seeleman, C. (2006). Shared decision-making in an intercultural context.

Barriers in the interaction between physicians and immigrant patients. *Patient Education and Counseling*, 60, 253-259. Doi: 10.1016/j.pec.2005.01.012

Thoits, P. A. (2011). Mechanisms linking social ties and support to physical and mental health.

Journal of Health and Social Behaviour, 52, 145-161. [doi:10.1177/0022146510395592](https://doi.org/10.1177/0022146510395592)

Tiggeman, M. & Williamson, S. (2000) The effect of exercise on body satisfaction and self-esteem as a function of gender and age. *Sex Roles*, 43, 119-127. doi:

10.1023/A:1007095830095

Towle, A., Godolphin, W., & Alexander, T. (2006). Doctor-patient communications in the

Aboriginal community: Towards the development of educational programs. *Patient Education and Counseling*, 62, 340-346. [doi:10.1016/j.pec.2006.06.006](https://doi.org/10.1016/j.pec.2006.06.006)

Townsend, L. (2009). The moralizing of obesity: A new name for an old sin? *Critical Social Policy*, 29, 171-190. Doi: 10.1177/0261018308101625

Turton, C. L. (1997). Ways of knowing about health: An Aboriginal perspective. *Advances in Nursing Science*, 19(3), 28-36. Retrieved from

http://journals.lww.com/advancesinnursingscience/Abstract/1997/03000/Ways_of_Knowing_about_Health_An_Aboriginal.4.aspx

Vasan, R. S., Beiser, A., Seshadri, S., Larson, M. G., Kannel, W. B., D'Agostino, R. B., ...Levy, D. (2002). Residual lifetime risk for developing hypertension in middle-aged women and men: The Framingham Heart Study. *Journal of the American Medical Association*, 287, 1003-1010. [doi:10.1001/jama.287.8.1003](https://doi.org/10.1001/jama.287.8.1003)

- Viswanathan, M., Ammerman, A., Eng, E., Gartlehner, G., Lohr, K., Griffith, D., ...Whitener, L. (2004). *Community-based participatory research: Assessing the evidence* (AHRQ Publication No. 04-A E022-2). Rockville, MD: Agency for Healthcare Research and Quality. Retrieved from <http://www.ahrq.gov/downloads/pub/evidence/pdf/cbpr/cbpr.pdf>
- Vital Statistics of the Saskatchewan Registered Indian Population. (2001). Saskatchewan: Medical Services Branch, Saskatchewan Regional Office.
- Waldram, J. B., & Layman, M. M. (1989). Health care in Saskatoon's inner city: A comparative study of Native and non-Native utilization patterns. *Native Issues*, 3, University of Manitoba: Institute of Urban Studies
- Whyte, W. F. (1991). *Participatory action research*. Thousand Oaks, CA: Sage Publications Ltd.
- Wikins, K., Campbell, N. R. C., Joffres, M. R., McAlister, F. A., Nichol, M., Quach, S., Johansen, H. L., ...Tremblay, M. S. (2010). Blood pressure in Canadian adults. *Health Reports*, 21, 1-10. Retrieved from http://publications.gc.ca/collections/collection_2010/statcan/82-003-X/82-003-x2010001-eng.pdf#page=39
- Wilson, P. M., Kendell, S., & Brooks, F. (2007). The expert patients programme: A paradox of patient empowerment and medical dominance. *Health and Social Care in the Community*, 15, 426-438. [doi:10.1111/j.1365-2524.2007.00701.x](https://doi.org/10.1111/j.1365-2524.2007.00701.x)
- Witmer, J. M., Hensel, M.R., Holck, P.S., Ammerman, A.S., & Will, J. C. (2004). Heart disease prevention for Alaska native women: A review of pilot study findings. *Journal of Women's Health*, 13, 569-578. [doi:10.1089/1540999041280981](https://doi.org/10.1089/1540999041280981)
- Woods, F. (2003). Access to food in Saskatoon's core neighbourhood. Community-University

- Institute for Social Research, University of Saskatchewan. Retrieved on March 27, 2012 from http://www.usask.ca/cuisr/docs/pub_doc/economic/WoodsFINAL.pdf
- World Health Organization. (1986). *The Ottawa charter for health promotion*. Retrieved from <http://www.who.int/healthpromotion/conferences/previous/ottawa/en/index.html>
- World Health Organization. (2008). *The final report of the commission on the social determinants of health*. Retrieved from http://www.who.int/social_determinants/thecommission/finalreport/closethegap_how/en/index1.html
- World Health Organization. (2009). *Global health risks: Mortality and burden of disease attributable to selected major risks*. Geneva: World Health Organization Press, 2009.
- Wurtzel, E. (1995). *Prozac nation*. New York, NY: Penguin Books Ltd.
- Yan, L.L., Liu, K., Matthews, K. A., Davigls, M. L., Ferguson, T. F., & Kiefe, C. I. (2003). Psychosocial Factors and Risk of Hypertension: The coronary artery risk development in young adults (CARDIA) study. *Journal of American Medical Association*, 290, 2138-2148. [doi:10.1001/jama.290.16.2138](https://doi.org/10.1001/jama.290.16.2138)
- Young, T. K. (1991). Prevalence and correlates of hypertension in a subarctic Indian population. *Preventive Medicine*, 20, 474-485. [doi:10.1016/0091-7435\(91\)90045-6](https://doi.org/10.1016/0091-7435(91)90045-6)
- Young, T. K., Moffatt, M. E. K., & O'Neil, J. D. (1993). Cardiovascular diseases in a Canadian arctic population. *American Journal of Public Health*, 83, 881-887.
- Young, T. K., Reading, J., Elias, B. & O'Neil, J. D. (2000). Type II diabetes mellitus in Canada's First Nations: Status of an epidemic in progress. *E-Canadian Medical Association Journal*, 163(5), 561-566. Retrieved from <http://www.ecmaj.ca/content/163/5/561.full>
- Zolnierok, K. B., & Dimatteo, M. R. (2009). Physician communication and patient adherence to

treatment: A meta-analysis. *Medical Care*, 47, 826–834. doi:[10.1097/MLR.0b013e31819a5acc](https://doi.org/10.1097/MLR.0b013e31819a5acc).

Appendix A

A Qualitative Inquiry of Aboriginal Peoples' Health Beliefs and Adherence to Treatment for Hypertension Student/Community Partnership Agreement February 12, 2009

Kristin Calverley, in collaboration with the advisory group members, agrees to conduct the named research project with the following understandings:

1. Objectives and Methods:

The development of this project is based on sincere communication between community members and the student researcher. All efforts will be made to incorporate and address the local community's concerns and recommendations at each step of the project.

The objectives of this research project are (a) to investigate how the diagnosis and treatment of hypertension is understood and experienced by Aboriginal peoples, (b) to gather the community's perspective on what changes need to be made for rates of hypertension to improve, and (c) to conduct an action research project to begin implementing these changes. The methods to be used, as agreed by the researchers and the community, are: interviews and action research dissemination methods to be determined from interview findings.

2. Commitment and Timeline:

The advisory group will meet approximately four times: prior to the recruitment and interviews taking place, after data collection and analysis, to assist in an action research dissemination plan, and at the conclusion of the project. The research project will be complete with the successful defense of the student researcher's dissertation. As of September 2010, the student researcher will be leaving Saskatoon in order to complete a clinical internship and any further consultation at this point will be done via email or phone.

3. Consent:

Informed consent of individual respondents is to be obtained in these agreed ways:

An individual consent form will be read by the interviewer to the respondent. A copy of the consent form will be left with the respondent where the address of each researcher can be used at any time, should the respondent wish to contact the researcher(s) for additional information. Translators will be provided as necessary. Depending on the action research dissemination strategy chosen, training will occur on an as-needed basis.

4. Data Storage, Access, and Confidentiality:

The data collected are confidential and no name will be attached to a record. Copies will be kept at the University of Saskatchewan where the data will be converted to an electronic form. The student researcher will be available to answer questions and assist community members should community members decide to use the data for different purposes. To fulfill my REB commitments, the data will be securely stored, and yet the community will always have access to them. The names of respondents are to be protected in these agreed ways: signed consent forms will be locked at the University of Saskatchewan, Department of Psychology. Electronic transcriptions and data analysis will use pseudonyms and no identifying information will be saved with the data. As mentioned on the consent form, the interviews are confidential. In no instance will the name of a respondent be attached to a record.

5. Dissemination of data:

Before distribution of the final report, or any publication or contact with the media, from either the student researcher or the advisory group, consultations will occur to ensure agreement of how data will be shared. Communication with the media and other parties (including funding agencies) outside the student researcher and the advisory group and/or community will be handled in these agreed ways: will occur only if both the student researcher and the advisory group are in agreement about the nature and content of this communication.

The study results will be disseminated to the Aboriginal community of Saskatoon. Exactly how they will be disseminated is yet to be determined; however, the most appropriate way to disseminate will be determined from the results of the interview data. Scientific presentations in peer-reviewed publications and conferences will be made after discussion and input from the advisory group members. The final dissertation will be reviewed by the advisory group prior to its completion and all input will be considered and acknowledged appropriately. The dissertation is subject to guidelines set forth by the College of Graduate Studies and Research and the student researcher may therefore be constrained by those guidelines.

6. Funding:

The student researcher has received funding for this research project from the Canadian Institutes for Health Research-Regional Partnership Program. Honorariums will be provided to all advisory group members.

Benefits

Kristin Calverley wishes to use this research project for her benefit in the following ways: to complete my doctoral dissertation, publish scholarly articles, present at conferences, and to disseminate the information to the community of Saskatoon (e.g., report, policy

recommendations, in-service to health region, photovoice, pamphlets for medical offices, etc).

The benefits likely to be gained by the community through this research project are:

- Educational
- Informational
- Health promotion
- Fostering self-determination
- Community development

Commitments

The advisory group's commitment to the student researcher is to:

- Recommend capable and reliable community members to be respondents or co-researchers
- Keep informed about the progress of the project, and help in leading the project toward meaningful results by offering input and feedback for the student researcher
- Assist in locating translators as needed

The student researcher's main commitment to the community is to:

- Agree to conduct the research, including conducting the interviews, doing data analysis, writing results, and facilitating the action research project
- Inform the advisory group about the progress at every major milestone of the research project, in a clear, specific, and timely manner
- Be available for questions and act as a resource for the duration of the project.
- Bring awareness to the issue of hypertension and health beliefs
- Respectfully address questions within a holistic health model and be open to diverse worldviews
- Gratefully acknowledge the work and assistance of all advisory group members and respondents in the dissertation or any other public work related to the project

The student researcher agrees to interrupt the research project in the following circumstances:

- If the advisory group decides to withdraw its participation.
- If the student researcher or the advisory group believes that the project is at all harmful and no longer benefits the community

Signed by:

Date:

Date:

Kristin Calverley
Ph.D. Candidate
Student Researcher

Danny Musqua
Traditional Research Methodologist/Elder
Advisory Group Member


Dr. Raven Sinclair
Assistant Director, IPHRC
Advisory Group Member

Jason Albert
President and Chairperson, SIMFC
Advisory Group Member

Sherri Pooyak
Community Research Facilitator, IPHRC
Advisory Group Member

Appendix B

Recruitment poster



Hypertension Study









Have you been diagnosed with high blood pressure or hypertension?
Are you Aboriginal?
Are you willing to discuss your experience?

I am conducting an interview study from March - May 2009 examining Aboriginal peoples' beliefs about, and experiences of, having hypertension. The goal of the study is to work toward reducing rates of hypertension. The interview will be approximately one hour in duration, and you will be paid \$20 for your time. If you have been diagnosed with hypertension and are Aboriginal, regardless of your treatment choices, I would like to hear your story.

To find out more, please contact:

Kristin Calverley, Ph.D. Candidate
966-6687 or kristin.calverley@usask.ca
Department of Psychology, University of Saskatchewan

This study is guided by an Aboriginal advisory group. For more information, please speak to Elder Danny Musqua, Professor Jason Albert, Dr. Raven Sinclair, or Sherry Pooyak. This study is also supported by the Canadian Institutes of Health Research and has been approved by the Behavioural Research Ethics Board of the University of Saskatchewan (966-2084).

Hypertension Study 966-6687	Hypertension Study 966-6687	Hypertension Study 966-6687	Hypertension Study 966-6687	Hypertension Study 966-6687	Hypertension Study 966-6687	Hypertension Study 966-6687	Hypertension Study 966-6687
							

Appendix C

Interview Question Guide

Demographic questions:

What is your name?

How old are you?

Where are you from? Where do you live now? For how long?

How many people do you currently live with?

Are you employed? If so, where? And for how long?

What is your education background?

How would you identify yourself in terms of Aboriginal heritage?

What is your first language? Do you speak any other languages? What language do you speak at home?

Do you have a vehicle?

Do you smoke? Drink alcohol?

Do you think you eat a balanced diet? Get regular exercise?

Do you feel busy lately? Do you worry a lot?

How do you fill your day?

Specific diagnostic questions:

Have you ever received a diagnosis of high blood pressure? How did that diagnosis come about? How did you and/or your doctor or nurse decide you might have high blood pressure? How? When was that diagnosis given? By whom?

How was hypertension explained to you?

What did you think of the diagnosis?

Have you ever thought you were not effectively diagnosed or treated for high blood pressure? How?

How do you understand high blood pressure? How? What does it feel like for you?

Do you have a family history of high blood pressure? How, diabetes, stroke, or kidney disease?

Treatment questions:

How was treatment explained to you?

What were your available options for treatment methods?

What was your decision around taking blood pressure pills/other treatment recommendations? What did you think about treatment? How long have you been taking it? Do you take them as prescribed?

Do you continue to see your physician/health provider about hypertension or other health problems?

Do you feel that your blood pressure is currently well-managed?

Have you ever seen a medicine keeper? Man/woman? If so, which ones, what was the outcome? How closely do you align yourself with Aboriginal worldviews of health?

Have you ever tried any alternative types of treatment? If so, which ones? What was the success of those?

What are your general thoughts about treatment?

Urban Aboriginal Peoples and Hypertension

If negative response: How does that affect your outcomes?

What do you think about taking pills? What do you think about seeing Medicine keepers?

Have you ever stopped taking your medication (or other form of treatment) without the consent of your doctor?

Have you ever treated yourself for high blood pressure? How without consulting your doctor? If so, what have you done? Was that successful?

Have you ever decided not to seek treatment for high blood pressure? How? How did you decide this and what were the outcomes?

How would you describe your relationship with your doctor with respect to being diagnosed and/or treated for high blood pressure? How?

Do you currently feel healthy? How do you maintain that?

Are others in your home healthy?

Action questions:

In light of your experiences with this discussion we have had around diagnosis and treatment for high blood pressure? How, is there anything you feel might have been done differently? What changes would you recommend for doctors? Others with this disease?

How easy is it for you to get to the doctor? What makes it easy/difficult? Other barriers to care? (lack of info, service delivery, relationships with doctors and nurses, etc.)

How often are you able to check your blood pressure? Where and when can you do that?

Do you think high blood pressure is a big problem for Aboriginal people?

How could awareness of this issue be increased?

Appendix D

Aboriginal advisory group Letter of Support

Saskatoon Indian and Métis Friendship Centre
168 Wall St.
Saskatoon, SK S7K 1N4
(306) 244-0174

University of Saskatchewan
Behavioural Research Ethics Board Office
University of Saskatchewan
Room 304 Kirk Hall, 117 Science Place
Saskatoon SK S7N 5C8

November 28, 2008

To Mr. Curtis Chapman;

Aboriginal communities in Saskatoon recognize that hypertension is an important co-morbid factor to local rates of diabetes, cardiovascular disease, kidney disease, and metabolic syndrome. As Aboriginal-held health beliefs in the area of hypertension diagnosis and treatment are not well understood, this is an important area of study.

We encourage partnerships at the University of Saskatchewan on this critical issue, and support the action research project proposed by Kristin Calverley (Ph.D. Candidate, Department of Psychology, University of Saskatchewan). The Saskatoon Indian and Métis Friendship Centre, a key organization in the urban Saskatoon Aboriginal community, is eager to be a part of a hypertension working group with other community partners such as the Student Wellness Initiative Toward Community Health (SWITCH), and the Indigenous Peoples' Health Research Centre (IPHRC). We look forward to tangible outcomes and raised awareness of the health status of urban Aboriginal peoples through these community and university partnerships.

Sincerely,

Jason Albert
President and Chairperson of Board of Directors
Saskatoon Indian and Métis Friendship Centre

Appendix E

REB Study Approval Form



UNIVERSITY OF
SASKATCHEWAN

Behavioural Research Ethics Board (Beh-REB)

Certificate of Approval

PRINCIPAL INVESTIGATOR
Linda McMullen

DEPARTMENT
Psychology

BEH#
09-19

INSTITUTION(S) WHERE RESEARCH WILL BE CONDUCTED
University of Saskatchewan
Saskatoon SK

STUDENT RESEARCHERS
Kristin Calverley

SPONSOR
CANADIAN INSTITUTES OF HEALTH RESEARCH (CIHR)

TITLE
A Qualitative Inquiry of Aboriginal Peoples' Health Beliefs and Adherence to Treatment for Hypertension

ORIGINAL REVIEW DATE
04-Feb-2009

APPROVAL ON
16-Mar-2009

APPROVAL OF:
Ethics Application
Consent Protocol

EXPIRY DATE
15-Mar-2010

Full Board Meeting

Date of Full Board Meeting:

Delegated Review

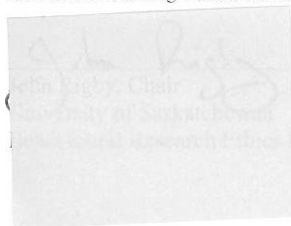
CERTIFICATION

The University of Saskatchewan Behavioural Research Ethics Board has reviewed the above-named research project. The proposal was found to be acceptable on ethical grounds. The principal investigator has the responsibility for any other administrative or regulatory approvals that may pertain to this research project, and for ensuring that the authorized research is carried out according to the conditions outlined in the original protocol submitted for ethics review. This Certificate of Approval is valid for the above time period provided there is no change in experimental protocol or consent process or documents.

Any significant changes to your proposed method, or your consent and recruitment procedures should be reported to the Chair for Research Ethics Board consideration in advance of its implementation.

ONGOING REVIEW REQUIREMENTS

In order to receive annual renewal, a status report must be submitted to the REB Chair for Board consideration within one month of the current expiry date each year the study remains open, and upon study completion. Please refer to the following website for further instructions: http://www.usask.ca/research/ethics_review/



Board

Please send all correspondence to:

Research Ethics Office
University of Saskatchewan
Box 5000 RPO University, 1602-110 Gymnasium Place
Saskatoon SK S7N 4J8

Appendix F

CONSENT FORM

You are invited to participate in a study entitled **A Qualitative Inquiry of Aboriginal Peoples' Health Beliefs and Adherence to Treatment for Hypertension.**

Researcher(s): Kristin Calverley, Ph.D. Candidate, Department of Psychology, University of Saskatchewan, 966-6687, kristin.calverley@usask.ca
Dr. Linda McMullen (Research Supervisor), Department of Psychology, University of Saskatchewan 966-6666, linda.mcmullen@usask.ca

Purpose and Procedure: The objective of this research is to investigate the lived experiences and understandings of Aboriginal people who have been diagnosed with hypertension. This study consists of a 1-2 hour individual interview pertaining to your experience with diagnostic and treatment practices associated with hypertension. The interview will be audio-recorded and then transcribed. You will later be asked to verify that the typed transcription of the interview was accurate and represents what you said. After completion of the interview, you will be given a summary of findings and recommendations upon request. The results of this research will be presented in traditional academic settings (e.g., at conferences, colloquia) and will be submitted for publication in peer-reviewed academic journals. In addition, they may be presented in more novel forms of dissemination and knowledge translation, such as community theatre, photovoice, documentary, policy recommendations, pamphlets for health clinics, etc. Data will be reported as direct quotations with all your identifying information removed.

Potential Benefits: Benefits of the research include the potential to inform respondents and health care professionals about the different (and sometimes conflicting) knowledge and experiences that are brought to bear in diagnostic or treatment decisions for hypertension, and to contribute to a greater understanding of ways in which professionals and Aboriginal people might work together more productively. As such, it holds the promise of leading to recommendation for improving the quality of care for hypertension in Aboriginal peoples. There is no guarantee that you will personally benefit from your involvement in this study.

Potential Risks: There are minimal anticipated risks in this study. Respondents will be aware of the purpose and why they are participating and may choose not to participate or respond without penalty. The interview respondents may experience some discomfort when recalling interactions with their health care provider at the time of diagnosis for and treatment of hypertension. If the discomfort appears to be substantial and warrant intervention, a list of health care professionals who provide services for emotional distress or health care will be provided.

Storage of data: During the study, all data (audio tapes, transcripts, notes, digital files) will be securely stored with Dr. Linda McMullen in the Department of Psychology.

Kristin Calverley and Dr. Linda McMullen will ensure that data are stored in a secured location for a minimum of five years after the completion of the study. When they data are no longer required, they will be destroyed.

Confidentiality: Measures will be taken to ensure the confidentiality of the respondents and of all data; however, anonymity cannot be promised. Data will be reported in the form of quotations, and all identifying information will be removed from the transcripts. Pseudonyms will be used in the place of real names. Nonetheless, respondents may be recognizable in the quotations, based on what they said during the interview. Only the student researcher, her supervisor and research team members, the translator (if required), and members of the participatory working group will have access to the data. All respondents in the advisory group will be asked to sign a confidentiality clause acknowledging his/her responsibility and agreement to protect the identity of the respondents and the confidentiality of all data, as well as the integrity and confidentiality of what others in the group have said during the meetings.

Right to Withdraw: Your participation is voluntary, and you can answer only those questions you are comfortable with. You may withdraw from the study for any reason, at any time, without penalty of any sort, until the dissertation is complete or data are published. Similarly, you may request that the audio recording devices be turned off at any point during the interview. If you withdraw from the study at any time, any data you have contributed will be destroyed at your request. The researcher will advise you of any new information that could influence your decision to participate in the ongoing parts of the study.

Compensation: You will be paid an honorarium of \$20 for your participation in the individual interview. Should you withdraw from the study before completing the interview, you will receive a pro-rated amount.

Questions: If you have any questions concerning the study, please feel free to ask at any point; you are also free to contact the researcher at the number and email address provided above if you have questions at a later time. This study has been approved on ethical grounds by the University of Saskatchewan Behavioural Research Ethics Board on March 16, 2009. Any questions regarding your rights as a respondent may addressed to that committee through the Ethics Unit (966-2084).

Follow-Up: Once the study is complete, a summary of the results will be available to respondents upon request.

Consent to Participate: I have read and understood the description provided; I have had an opportunity to ask questions and my questions have been answered. I consent to participate in the research project, understanding that I may withdraw my consent at any time. A copy of this Consent Form has been given to me for my records.

Urban Aboriginal Peoples and Hypertension

(Name of Respondent)

(Date)

(Signature of Respondent)

(Signature of Researcher)

Appendix G

**Transcript Release Form
A Qualitative Inquiry of Aboriginal Peoples' Health Beliefs and
Adherence to Treatment for Hypertension**

I _____, have reviewed the complete transcript of my personal interview in this study, and have been provided with the opportunity to add, alter, delete information from the transcript as appropriate. I acknowledge that the transcript accurately reflects what I said in my personal interview with Kristin Calverley. I hereby acknowledge the release of this transcript to Kristin Calverley to be used in the manner described in the consent form. I have received a copy of this Transcript Release Form for my own records.

(Name of Respondent)

(Date)

(Signature of Respondent)

(Signature of Researcher)

Appendix H

Action Suggestions

More and better quality information: Awareness and Education Campaigns

- Education-doctors could spend more time on this.
- Quality not quantity of information-knowledge translation...making info meaningful.
- Repeated exposure to information...more discussions
- Better explanation of symptoms, cause, etc. Understanding why condition exists or is caused, how to control it, and why it persists.
- More info needed about alternatives and lifestyle modifications beyond pills
- Reading material: internet sources/ Helping to provide access to printed internet material (difficult if don't have home computer or printer)
- Information visible in places Aboriginal people frequent rather than general locations
- Pamphlet/Specific pamphlet for Aboriginal hypertension
- CBC commercial
- Articles in Eagle feather news
- Afternoon workshop with docs, other specialists, held at St. Paul's etc
- Signs at medical centres & pharmacies
- Posters on bus
- Better info for pharmacies: adjustable seat, 3 readings, etc

Doctor Patient Relationship: Better and More Thorough Care

- More regular check ins with doctor = better maintenance
 - Improve relationships between Docs and Aboriginal patients to improve communication and trust
 - Stronger relationship with doctor so that doc can be more familiar with pt's history
 - Have docs take time to ask what else is going on-misdiagnosis due to hangovers etc.
 - Need to address alcoholism, mood problems first then high bp will resolve.
- Priorities of treatment
- If someone is homeless or drug abusing, treatment needs to be modified or made to suit individual.

Enhanced clearer communication with health professionals

- Respect patients by communicating to their level
- Prevention versus awareness and treatment
- Specific and concrete recommendations, rather than general statements: take care of yourself, lose weight, eat better
- Doctors need better social skills: look patients in the eye, really listen, be helpful and offer suggestions not orders

Other

- Assistance with lifestyle change
- Pill recording devices: charts, bubble packs etc.
- Pills aren't the solution if someone's homeless

Urban Aboriginal Peoples and Hypertension

Talking circles

Collaboration with dietitians, nutritionists, exercise therapists

Walking groups-within accessible distance

Relapse prevention because of negative side-effects

Social support to make changes

Needing affordable fruits and veggies, leisure passes, bus passes

Appendix I

Focus Group Consent Form

You are invited to participate in a study entitled **A Qualitative Inquiry of Aboriginal Peoples' Health Beliefs and Adherence to Treatment for Hypertension.**

Researcher(s): Kristin Calverley, Ph.D. Candidate, Department of Psychology, University of Saskatchewan, 966-6687, kristin.calverley@usask.ca
Dr. Linda McMullen (Research Supervisor), Department of Psychology, University of Saskatchewan 966-6666, linda.mcmullen@usask.ca

Purpose and Procedure: The objective of this research is to investigate the lived experiences and understandings of Aboriginal people who have been diagnosed with hypertension.

Following up from the individual interview you participated in last year, we now invite you to participate in a **1-2 hour focus group**. During this session, the researcher will facilitate a group discussion about how to select community-based interventions that best suit the needs of raising awareness and preventing hypertension in the Aboriginal community of Saskatoon. The ideas for the intervention project were generated from all the interview respondents' responses during the individual interviews, yet a more structured and directed group discussion will occur. This focus group session will be audio recorded and then transcribed into a written document.

Potential Benefits: Benefits of the research include the potential to inform respondents and health care professionals about the different (and sometimes conflicting) knowledge and experiences that are brought to bear in diagnostic or treatment decisions for hypertension, and to contribute to a greater understanding of ways in which professionals and Aboriginal people might work together more productively. As such, it holds the promise of leading to recommendations for improving the quality of care for hypertension in Aboriginal peoples. There is no guarantee that you will personally benefit from your involvement in this focus group.

Potential Risks: There are minimal anticipated risks in this study. Respondents will be aware of the purpose and why they are participating and may choose not to participate or respond without penalty. The focus group respondents may experience some discomfort when discussing the health of the community. If the discomfort appears to be substantial and warrant intervention, a list of health care professionals who provide services for emotional distress or health care will be provided.

Storage of data: During the study, all data (audio tapes, transcripts, notes, digital files) will be securely stored with Dr. Linda McMullen in the Department of Psychology. Kristin Calverley and Dr. Linda McMullen will ensure that data are stored in a secured location for a minimum of five years after the completion of the study. When they data are no longer required, they will be destroyed.

Confidentiality: Measures will be taken to ensure the confidentiality of the respondents and of all data; however, anonymity cannot be promised. Data will be reported in the form of quotations, and all identifying information will be removed from the transcripts. Pseudonyms will be used in the place of real names. Nonetheless, respondents may be recognizable in the quotations, based on what they said during the focus group. Only the student researcher, her supervisor and research team members, the translator (if required), and members of the Aboriginal advisory group will have access to the data. All respondents in the advisory group will be asked to sign a confidentiality clause acknowledging his/her responsibility and agreement to protect the identity of the respondents and the confidentiality of all data, as well as the integrity and confidentiality of what others in the group have said during the meetings. The results of this research will be presented in traditional academic settings (e.g., at conferences, colloquia) and will be submitted for publication in peer-reviewed academic journals

With respect to the focus group, respondents will likely learn one another's names in order to facilitate the group discussion. In the case of these groups, anonymity cannot be guaranteed, and there are limits to which the researcher can ensure the confidentiality of the information shared. You will be asked to sign a confidentiality clause acknowledging your responsibility and agreement to protect the identity of the other respondents as well as the integrity and confidentiality of what others in the group have said during the research sessions. While this procedure is designed to safeguard the confidentiality of the discussion, we cannot guarantee that other members of the group will do so. Please respect the confidentiality of the other members of the group by not disclosing the contents of this discussion outside the group, and be aware that others might not respect your confidentiality.

Right to Withdraw: Your participation is voluntary, and you can answer only those questions you are comfortable with. You may withdraw from the focus group for any reason, at any time, without penalty of any sort, until the dissertation is complete or data are published. Similarly, you may request that the audio recording devices be turned off at any point during the focus group. If you withdraw from the focus group at any time, any data you have contributed will be destroyed at your request. The researcher will advise you of any new information that could influence your decision to participate in the ongoing parts of the focus group.

Compensation: You will be paid an honorarium of \$20 for your participation in the focus group. Should you withdraw from the focus group before its completion, you will receive a pro-rated amount.

Questions: If you have any questions concerning the study, please feel free to ask at any point; you are also free to contact the researcher at the number and email address provided above if you have questions at a later time. This study has been approved on ethical grounds by the University of Saskatchewan Behavioural Research Ethics Board on April 1, 2010. Any questions regarding your rights as a respondent may be addressed to that committee through the Ethics Unit (966-2084).

Urban Aboriginal Peoples and Hypertension

Follow-Up: Once the entire study is complete, a summary of the results will be available to respondents upon request.

Consent to Participate: I have read and understood the description provided; I have had an opportunity to ask questions and my questions have been answered. I consent to participate in the research project, understanding that I may withdraw my consent at any time. A copy of this Consent Form has been given to me for my records.

(Name of Respondent)

(Date)

(Signature of Respondent)

(Signature of Researcher)

Appendix J

Confidentiality Clause (Focus Group Respondents)
A Qualitative Inquiry of Aboriginal Peoples' Health Beliefs and Adherence to Treatment for Hypertension.

I, _____, acknowledge my responsibility and agreement to protect the identity of the respondents and other members of the focus group, as well as the integrity and confidentiality of the data and what others in the group have said during the meetings.

(Name of Respondent)

(Date)

(Signature of Respondent)

(Signature of Researcher)

Appendix K

Confidentiality Clause (Aboriginal Advisory Group)
A Qualitative Inquiry of Aboriginal Peoples' Health Beliefs and Adherence to Treatment
for Hypertension

I, _____, acknowledge my responsibility and agreement to protect the identity of the respondents and other members of the advisory group, as well as the integrity and confidentiality of the data and what others in the group have said during the meetings.

(Name of Respondent)

(Date)

(Signature of Respondent)

(Signature of Researcher)

Appendix L

Analysis Codes

Access issues
Addictions
Adherence
Adverse side-effects
Advice for other people
Approach to treatment
Avoidance behaviour
Awareness of issue
Balance
Barriers
Beliefs about causality of hypertension
Beliefs about health
BP
BP monitoring frequency
Chaotic lives
Codependency
Collaborative relationship with physician
Communication with physician
Confidence in physician
Connection to Aboriginal heritage
Conspiracy theory-Anti biomedical approach
Control and self-empowerment
Depressed mood
Diagnostic impressions
Diet
Distrust of health care providers
Economic stability
Family
Family medical history
Fatalistic attitude
Fear
Financial insecurity
Forensic and Legal issues
Genetic contribution to hypertension
Giving back to society
Healthy lifestyle choices
Healthy scepticism
Hope
Idealized view of self
Importance of health
Increasing awareness tips
Intentions to become healthy
Lack of emphasis on health-different priorities

Lack of identification with Aboriginal identity
Lack of information
Lack of time allotted to patients
Longstanding hypertension
Medicine keepers
Miscommunication with doctor
Misdiagnosis
Morality & Health
Motivation
Non-biomedical treatment approaches
Pills
Political ideas
Poor lifestyle choices
Psychosocial issues impacting health
Related medical concerns
Resistance to taking medications
Self-responsibility for health status
Shame
Social support
Spirituality
Stress or Worry
Symptoms of hypertension
Treatment understanding
Trust in health provider
Turning point- telling moment
Understanding of consequences of untreated hypertension
Victim

Appendix M

Themes

Barriers to care

Cultural, socioeconomic, and psychological factors affecting health

Lay and expert knowledge: Relationships and health care encounters

Lifestyle and social determinants of health

Morality and health

Self-determination and passive agency

Power relations in health care/colonialism

Treatment: Relationship to pills

Appendix N
Indigenous Times Article

has several suggestions on taking our local economy global. Some of the national enterprises (Shuman, p. 110), long-term governments need to comply with outstanding land claims, realistic Social Economy maynayers

Hypertension Affecting the Aboriginal Community at Higher Rates

Student's research compares individual and societal determinants of individual health

BY KRISTIN CALVERTLEY

My name is Kristin Calvertley and I am a Ph.D. student from the Department of Psychology at the University of Saskatchewan. I decided to embark on a life-changing research endeavour in 2005 when I moved to Saskatoon and became involved in local issues affecting the health of residents of the city's core neighbourhoods, particularly with my involvement with the Student Wellness Initiative Toward Community Health (SWITCH). As such, I decided to orient my doctoral research to understanding how hypertension (high blood pressure) and its treatment is understood by Saskatchewan Aboriginal communities as the prevalence of hypertension is now higher in Aboriginal peoples than non-Aboriginal peoples in Canada.

Hypertension is a chronic disease that affects 20% of the Canadian population aged 18-79 years. The Heart & Stroke Foundation of Canada has identified it as a major risk factor for heart disease and stroke, both of which are among the leading causes of death in Canadians. Hypertension is also a major risk factor for kidney failure/ disease, erectile dysfunction, and diabetes. It tends to be caused by a combination of factors including an inactive lifestyle, poor diet, obesity, high alcohol or sodium intake, excessive caffeine consumption, diabetes, stress, and smoking.

The initial part of this study comprised individual interviews with 11 urban Aboriginal people with hypertension about their beliefs and perspectives regarding the diagnosis and treatment of hypertension. A year later, a focus group was held with a small number of the original participants to review the analysis and make a plan to disseminate the results (action research). This study was guided by an Aboriginal advisory group in order to ensure that it was ethically and culturally appropriate, composed of Elder Danny Musqua, Dr. Raven Sinclair, Sherry Pooyak, Jason Albert, and me.

My analysis showed that poor health was clearly seen as an individual responsibility (i.e., blaming the individual) which led to a range of participant experiences. For instance, shame, ambivalence, anger, and disappointment were all associated with health care encounters and biomedical frameworks for health. However, by taking responsibility for one's health, the participants also expressed feeling in charge, hopeful, proud, and confident. Overall, there are both positive and negative outcomes of adopting a biomedical discourse toward health for urban Aboriginal peoples.

Even though past research shows that health is strongly influenced by social determinants of health—especially income—rather than individual factors, my research showed that for many urban Aboriginal peoples the responsibility for health remains on the individual. Current health promotion strategies tends to focus on individual rather than broader, societal-based health. Yet, when basic needs are unmet, including housing, employment, or food security, one's capacity to consider factors such as diet, physical activity, and medication adherence is challenged. The implications of these findings are striking: individuals efforts toward health promotion may be ineffective if health is significantly influenced by broad and societal-based factors. Ideal interventions would therefore consider both individual factors (such as education about healthy eating and increasing physical activity) along with societal-based factors that contribute to urban Aboriginal peoples' health. For instance, providing services within walking distance or access to healthy food within low-income neighbourhoods needs to be prioritized along with medical provision.

The present study also examined how lay and expert knowledge is negotiated within health care encounters. Findings demonstrated that, overall, the participants were well informed, savvy, and held expert knowledge of their health primarily within a biomedical framework. Sometimes, though, the participants wanted more specific and accessible information about hypertension and treatment issues. Further, other times they lacked access (e.g., no transportation, inadequate time and energy, etc.) or the desire to pursue such information. Similarly, my study found that medical expertise held by physicians was viewed as privileged over the patients' lay knowledge, which highlights and supports the persistence of power imbalances and colonial exchanges within health care encounters with Aboriginal patients.

In addition, my findings revealed that holding sophisticated biomedical knowledge does not necessarily equal adherence to treatment. Instead, adherence was confounded by other factors, such as self-blame for poor health, stigmatization, access issues, colonialism, and power imbalances. Therefore, in order to strengthen current interventions, researchers and health care practitioners need to be increasingly sensitive to these factors within health care encounters with Aboriginal patients.

Overall, this dissertation highlighted important implications about the nature of our current approaches to health and possibilities for future intervention and policy development. Although the participants in this study did not tend to favour Aboriginal ceremonial and natural forms of healing over biomedical approaches to treating hypertension, they preferred interventions to be collective rather than individual, involve nature, and address emotional needs. As tremendous diversity and variability exists among urban Aboriginal patients' beliefs and orientations toward their health, my findings confirm that such diversity is crucial to consider during health care encounters as a single approach will not suit the needs of all Aboriginal patients. Promoting discussion of patients' beliefs toward disease and attitudes about treatment for hypertension is tremendously important for health care providers and such discussions might reveal potential barriers to adherence.

This research was very rewarding and was only possible due to the commitment of the communities who engaged with the research. As the research was community-based, I am disseminating the research findings to various Aboriginal health organizations and to the Saskatchewan Ministry of Health. If you have any questions regarding this research, please contact Kristin.calvertley@usask.ca.

Appendix O

Urban Aboriginal Peoples' Health Beliefs and Adherence to Treatment for Hypertension

EXECUTIVE SUMMARY

The purpose of this summary is twofold: (1) to disseminate the findings of my dissertation to enhance awareness about hypertension among urban Aboriginal peoples and (2) to inform future policy and intervention programs to help reduce rates of hypertension.

Also known as high blood pressure, hypertension is a chronic disease that affects 20% of the Canadian population aged 18-79 years. It is a major risk factor for heart disease and stroke, both of which are among the leading causes of death in Canadians (Heart & Stroke Foundation of Canada [HSFC], 2010, 2011).

Hypertension is a chronic condition resulting from excessive and prolonged pressure in the walls of the blood vessels as blood circulates or when cardiac output is excessive and increased blood flow puts an overload of pressure on the arterial walls (The Canadian Hypertension Society [CHS], 2011; Public Health Agency of Canada [PHAC], 2010). It is often defined as systolic blood pressure ≥ 140 mm HG or diastolic blood pressure ≥ 90 mm HG (HSFC, 2011). This chronic disease tends to affect people after age 35 with higher prevalence rates among men than women, until menopause at which point the prevalence becomes higher in women. About 30% of people have a family history of the disease.

Hypertension is a major risk factor for congestive heart failure, dyslipidemia (high lipid count), coronary artery disease, atrial fibrillation (an irregular and often rapid heartbeat), glucose intolerance, insulin resistance, renal failure or disease, erectile dysfunction, and diabetes (CHEP, 2012; HSFC, 2003; PHAC, 2010). Known causes include a combination of sedentary lifestyles, poor diet, obesity, high alcohol or sodium intake, excessive caffeine consumption, diabetes, stress, and smoking (CHEP, 2012; HSFC, 2011). The majority of these risk factors are both preventable and modifiable. In the past two decades, the prevalence of hypertension among Aboriginal peoples has significantly risen and is now higher than in the non-Aboriginal population (e.g., 20% compared to 16.4%) (HSFC, 2006; First Nations Centre, 2006).

The present study investigated the ways in which urban Aboriginal persons and members of an Aboriginal advisory group oriented themselves toward conversations about hypertension. In 2009, I interviewed 11 urban Aboriginal people with hypertension living in Saskatoon about their beliefs and perspectives regarding the diagnosis and treatment of hypertension. A year later, a focus group was held with a small number of the original respondents to review the analysis and make a plan to disseminate the results (action research). This study was guided by an Aboriginal advisory group in order to ensure that it was ethically and culturally appropriate.

My analysis showed that poor health was clearly seen as an individual responsibility (i.e., blaming the individual); even when the respondents challenged this discourse, their arguments were still organized around the biomedical and individualist frameworks of health. This orientation toward a biomedical framework for diagnosis, knowledge of, or treatment for

hypertension led to a range of respondent experiences. For instance, shame, ambivalence, anger, and disempowerment were all associated with health care encounters and biomedical frameworks for health. However, by taking responsibility for one's health, the respondents also expressed feeling empowered, hopeful, proud, and confident. Therefore, adoption of biomedical discourses of health might be both beneficial and detrimental for urban Aboriginal peoples.

Robust research evidence suggests that health is strongly influenced by the social determinants of health --especially income-- rather than individual factors (National Aboriginal Health Organization [NAHO], 2006; PHAC, 2003a, 2003b; Raphael, 2009; World Health Organization [WHO], 2008). Nevertheless, for many urban Aboriginal peoples, --as revealed by the findings of the present research-- the responsibility for health remains imposed on the individual. Current health promotion strategies tend to focus on individual rather than broader, societal-based health. Yet, when basic needs are unmet, including housing, employment, or food security, one's capacity to consider factors such as diet, physical activity, and medication adherence is challenged.

The implications of these findings are striking: individual efforts toward health promotion may be futile if health is significantly influenced by social determinants and macro-level factors. It would be unrealistic to ignore the impact and dominance of a biomedical framework for understanding and treating hypertension. As such, improving individuals' health through traditional health promotion efforts is still necessary and will benefit individuals. Ideal interventions would therefore jointly consider individual factors (such as education about healthy eating and increasing physical activity) along with macro-level factors that contribute to urban Aboriginal peoples' health (Herr & Anderson, 2005). For instance, providing services within walking distance or access to healthy food within low-income neighbourhoods needs to be prioritized along with medical interventions.

The present study also examined how lay and expert knowledge is negotiated within health care encounters. Findings demonstrated that, overall, the respondents were well informed, savvy, and held expert knowledge of their health primarily within a biomedical framework. Despite this, they desired more specific and accessible information about hypertension and treatment issues. Likewise, although respondents were highly resourceful and mostly willing to seek out expert knowledge or highly technical information, not all had access (e.g., no transportation, inadequate time and energy, etc.) or the desire to pursue such information. Consequently, lack of patient access to information was a prominent barrier to health improvement. Similarly, the present findings suggest that medical expertise held by physicians remains privileged over the patients' lay knowledge, which highlights and supports the persistence of power imbalances and colonial exchanges within health care encounters with Aboriginal patients.

In addition, the present research findings indicate that holding sophisticated biomedical knowledge does not necessarily equal adherence to treatment. Instead, findings revealed that adherence is confounded by other factors, such as self-blame for poor health, stigmatization, access issues, colonialism, and power imbalances. Therefore, in order to enhance the effectiveness, efficacy, and significance of current interventions, researchers and health care practitioners need to be increasingly sensitive to these factors within health care encounters with Aboriginal patients.

Overall, this dissertation revealed important implications about the nature of our current approaches to health and possibilities for future intervention. Although the respondents in this study did not tend to favour Aboriginal ceremonial and natural forms of healing over biomedical approaches to treating hypertension, they did prefer interventions to be collective rather than individual, involve nature, and address emotional needs. Such recommendations align with a medicine wheel approach that fosters a holistic treatment of health.

Tremendous diversity and variability exists among urban Aboriginal patients' beliefs and orientations toward their health. The findings from the present research confirmed that such diversity is crucial to consider during health care encounters as a single approach will not suit the needs of all Aboriginal patients. Promoting discussion of patients' beliefs toward disease and attitudes about treatment for hypertension is tremendously important for health care providers and such discussions might reveal potential barriers to adherence.

Given this knowledge, the findings in this study, taken in combination with converging past research, support a pivotal role for a macro-level understanding of Aboriginal peoples' health, along with engaging communities in community-based approaches to hypertension intervention. This study is important in informing the provision of future community-based interventions for hypertension within Aboriginal communities that emphasize community engagement, access, and holistic health; such interventions will align with the ideal: including the social and Aboriginal determinants of health in our interventions.

Based on Doctoral dissertation by Kristin L. Calverley
Department of Psychology
University of Saskatchewan
July 2012

REFERENCES

- Canadian Hypertension Education Program. (2012). *The 2012 CHEP recommendations*. Retrieved from <http://www.hypertension.ca/chep-recommendations>.
- Canadian Hypertension Society. (2011). *What is hypertension?* Retrieved from <http://www.hypertension.ca/what-is-hypertension-dp1>
- First Nations Centre. (2006). *First Nations regional longitudinal health survey (RHS): The peoples' report*. Ottawa, ON: Assembly of First Nations. Retrieved from http://www.rhs-ers.ca/sites/default/files/ENpdf/RHS_2002/rhs2002-03-the_peoples_report_afn.pdf
- Heart and Stroke Foundation of Canada. (2003). *The growing burden of heart disease and stroke in Canada in 2003*. Report retrieved from http://www.cvdinfobase.ca/cvdbook/CVD_En03.pdf
- Heart and Stroke Foundation of Canada. (2006). *Tipping the scales of progress: Heart disease and stroke in Canada 2006*. Report retrieved from http://www.heartandstroke.com/atf/cf/%7B99452D8B-E7F1-4BD6-A57D-B136CE6C95BF%7D/Tipping_the_Scales_new.pdf
- Heart and Stroke Foundation of Canada. (2010). *Heart and Stroke Foundation research report*. Report retrieved from http://hsf.ca/research/sites/default/files/HSFC_ResearchReport%20_Eng_2009-2010.pdf

- Heart and Stroke Foundation of Canada. (2011a). *High blood pressure*. Report retrieved from http://www.heartandstroke.mb.ca/site/c.lgLSIV0yGpF/b.3661255/k.EE9/Stroke_High_blood_pressure_hypertension.htm
- Herr, K. & Anderson, G. L. (2005). *The action research dissertation: A guide for students and faculty*. Thousand Oaks, CA: Sage Publications Ltd.
- National Aboriginal Health Organization. (2006). *Broader determinants of health in an Aboriginal context*. Retrieved June 16, 2009 from http://www.naho.ca/english/pdf/2006_Broader_Determinants.pdf
- Public Health Agency of Canada. (2003a). *Population health: Determinants of health*. Retrieved from <http://www.phac-aspc.gc.ca/ph-sp/phdd/determinants/index.html#determinants>
- Public Health Agency of Canada. (2003b). *What determines health?* Retrieved from <http://www.phac-aspc.gc.ca/ph-sp/determinants/index-eng.php>
- Public Health Agency of Canada. (2010). *Report from the Canadian chronic disease surveillance system: Hypertension in Canada 2010*. Retrieved from http://www.phac-aspc.gc.ca/cd-mc/cvd-mcv/ccdss-snsmc-2010/pdf/CCDSS_HTN_Report_FINAL_EN_20100513.pdf
- Raphael, D. (Ed.) (2009). *Social determinants of health: Canadian perspectives, 2nd Edition*. Toronto, ON: Canadian Scholars' Press Inc.
- World Health Organization. (2008). *The final report of the commission on the social determinants of health*. Retrieved from http://www.who.int/social_determinants/thecommission/finalreport/closethegap_how/en/index1.html