# PERSPECTIVES OF URBAN ABORIGINAL PEOPLE WITH DIABETES

### **REGARDING APPROPRIATE HEALTH SERVICES**

by

## Gillian Tyson

B.Sc., University of Alberta, 1994

# THESIS SUBMITTED IN PARTIAL FULFILLMENT OF

# THE REQUIREMENTS FOR THE DEGREE OF

## MASTER OF SCIENCE

in

### COMMUNITY HEALTH SCIENCE

### THE UNIVERSITY OF NORTHERN BRITISH COLUMBIA

August 2004

© Gillian Tyson, 2004



Library and Archives Canada

Published Heritage Branch

395 Wellington Street Ottawa ON K1A 0N4 Canada Bibliothèque et Archives Canada

Direction du Patrimoine de l'édition

395, rue Wellington Ottawa ON K1A 0N4 Canada

> Your file Votre référence ISBN: 0-494-04662-7 Our file Notre référence ISBN: 0-494-04662-7

# NOTICE:

The author has granted a nonexclusive license allowing Library and Archives Canada to reproduce, publish, archive, preserve, conserve, communicate to the public by telecommunication or on the Internet, loan, distribute and sell theses worldwide, for commercial or noncommercial purposes, in microform, paper, electronic and/or any other formats.

The author retains copyright ownership and moral rights in this thesis. Neither the thesis nor substantial extracts from it may be printed or otherwise reproduced without the author's permission.

# AVIS:

L'auteur a accordé une licence non exclusive permettant à la Bibliothèque et Archives Canada de reproduire, publier, archiver, sauvegarder, conserver, transmettre au public par télécommunication ou par l'Internet, prêter, distribuer et vendre des thèses partout dans le monde, à des fins commerciales ou autres, sur support microforme, papier, électronique et/ou autres formats.

L'auteur conserve la propriété du droit d'auteur et des droits moraux qui protège cette thèse. Ni la thèse ni des extraits substantiels de celle-ci ne doivent être imprimés ou autrement reproduits sans son autorisation.

In compliance with the Canadian Privacy Act some supporting forms may have been removed from this thesis.

While these forms may be included in the document page count, their removal does not represent any loss of content from the thesis.



Conformément à la loi canadienne sur la protection de la vie privée, quelques formulaires secondaires ont été enlevés de cette thèse.

Bien que ces formulaires aient inclus dans la pagination, il n'y aura aucun contenu manquant. Abstract

The purpose of this study was to explore urban Aboriginal people's perspectives on diabetes and their experiences using health services. Using a qualitative approach, in-depth semi-structured interviews were conducted with eight urban Aboriginal people with diabetes. The data generated were analyzed using content analysis. The findings indicate that urban Aboriginal people have difficulty accessing and navigating health care services as result of social, cultural, and economic circumstances. Further, lack of resources and information appropriate to participants' needs created difficulties in their making lifestyle changes for diabetes management. Emphasized was the need for greater diabetes awareness and availability of suitable resources for the Aboriginal community. In the discussion, the new paradigm of chronic disease management, with emphasis on self-management, is explored as an approach to change the health care system and make improvements to diabetes care services that positively contribute to Aboriginal people's health. Based on the results, implications for programs and services, health care providers, and further research are presented.

ii

# TABLE OF CONTENTS

Abstract	ii	
Table of Contents	iii	
List of Figures	v	
Acknowledgements	vi	
Chapter 1		
Introduction	1	
Background to the Problem	3	
Diabetes in Canadian Aboriginal populations	4	
Diabetes in British Columbia Aboriginal populations	9	
Aboriginal people's diabetes experience	10	
Community Profile	12	
Study Purpose	13	
Research Question	13	
Framework of the Thesis	14	
Chapter 2		
Literature Review	15	
Aboriginal Perspectives About Diabetes	15	
Urban Aboriginal People's Experiences of Health Services	19	
Diabetes Care	23	
Aboriginal People's Experience of Diabetes Care	25	
Chronic Disease Management	30	
Self-management	34	
Self-management education	35	
Summary	39	
Chapter 3		
Methods	40	
Participants	41	
Data Collection	44	
Ethical Considerations	47	
Data Analysis	49	
Reliability and validity	51	
Summary	52	
Chapter 4		
Participants' Experience with Diabetes and Health Services	53	
Coming to Diagnosis		

	Body changes	54
	Attending to changes: Community awareness of diabetes	56
	Personal awareness of diabetes	58
	Seeking help	60
	Prior experiences with the health system	62
	Experience of diagnosis	65
Taking Control		
-	Loss of traditional lifestyle	68
Experience of Health Care and Diabetes Education		70
	Relations with health care providers	71
	Accessibility	73
	Feeling welcome	75
	Health literacy	77
	Learning practical self-care skills	79
	Successful learning methods	80
	Follow-up	82
	Cultural appropriateness	84
	Cultural considerations	86
Challer	iges to Self-Care	89
	Personal reactions	91
	Social circumstances	93
	Expense of self-care	94
Summary		
Chapter 5		
Discussion and Conclusions		98
Naviga	ting Health Resources	100
Interact	tions with Health Care Providers	105
Implica	tions	109
	Implications for programs and services	109
	Implications for health care providers	113
Implications for Further Research		114
Conclusions		115
References		116
Appendix A	Copyright Permission Letter	127
Appendix B	Copyright Permission Letter	129
Appendix C	Interview Questions	131
Appendix D	Explanation to the Participants of the Study	133
Appendix E	Informed Consent and Agreement to Participate	136
Appendix F	Memorandum of Agreement	139

Figure 1	Prevalence of Self-reported Diabetes Mellitus among all Canadians (1994) and First Nations people (1991 and 1997).	6
Figure 2	Chronic Disease Prevention and Management Model	32

#### Acknowledgements

I would first like to thank the participants of my study for sharing with me their stories. I sincerely thank the Central Interior Native Health Society for their support of my research by assisting in recruitment of participants, providing me with space for interviews, and generally welcoming me to learn about urban Aboriginal health care.

I am particularly indebted to my supervisor Martha Macleod for her patience, guidance, and commitment to my endeavor to complete my thesis. I am also grateful to my committee members Cindy Hardy, Monty Palmantier, and Lorna Medd for their valuable ideas and suggestions. And, I would like to acknowledge Annette Browne and Dana Edge for their support during early stages of this study.

To my husband Leo, family and friends – I couldn't have made it without your words of encouragement and confidence in me. Special thanks to my Mom, Sandy, and Robert for reviewing previous drafts.

vi

#### Chapter 1: Introduction

Diabetes has been identified as a problem of epidemic proportion for Aboriginal people throughout Canada that is further compounded by a lack of adequate diabetes programs, services and resources for Aboriginal peoples. Aboriginal people generally have limited interest in the support services of the mainstream health care system. In their experience such services, including those for people with diabetes, have been ineffective in improving their health (Aboriginal Health Association of British Columbia [AHABC], 1999; B. C. First Nations Regional Health Survey [BCFNRHS], 2000; Bobet, 1998; British Columbia Provincial Health Officer [BCPHO], 2002). This is the case even in urban settings (Gregory et al., 1999; Royal Commission on Aboriginal Peoples [RCAP], 1996; Shestowsky, 1995). In general, research has shifted from inquiry about patient noncompliance with diabetes care to questions investigating problems with the diabetes care model (Anderson, 1985; Glasgow & Anderson, 1999; Paterson, 2001; Wagner et al., 2001). One main outcome identified by such studies has been the need to educate and support people with diabetes to manage their disease in the context of their daily lives. With Aboriginal people experiencing high and steadily increasing rates of diabetes and associated complications, special health programs which promote prevention and support Aboriginal people in British Columbia to deal with the everyday dilemmas surrounding diabetes are of utmost importance.

This is a descriptive exploratory qualitative study of the perspectives of urban Aboriginal people in Prince George, British Columbia about diabetes and their experiences using health services. The initial idea for conducting this study came out of my volunteer work with the Canadian Diabetes Association that included an opportunity to present with a nurse educator about diabetes to a group of Aboriginal people at the local college. The students in this group said that the problem of diabetes in their community was accelerating, and that awareness of diabetes was limited. Consultation with the Central Interior Native Health Society (CINHS) confirmed the reports of an increasing rate of diabetes among their clients, and growing requests for diabetes health care and health education services. Due to limited time, staff, and resources, the CINHS was, at the time, only able to provide the most basic information to clients. In Prince George, Aboriginal people with diabetes were receiving little, if any, diabetes education. Members of the health community reported Aboriginal people seldom used the diabetes education clinic at the Prince George Regional Hospital or the local branch of the Canadian Diabetes Association. This process raised the question whether the contemporary model of diabetes care is sufficient to meet the needs of urban Aboriginal people in Prince George, and whether new culturally sensitive and accessible diabetes education and management programs were required. In order to answer these questions, information was needed regarding the experiences of urban Aboriginal people with diabetes and their perspectives about the currently offered health services.

Aboriginal people in Canada have varying differences in status and entitlement, a result of discriminatory labelling by the federal government Indian Act (RCAP, 1996). For the purposes of this study the term "Aboriginal people" will be used to collectively represent all First Nations (status and non-status) and Métis people. Inuit people, although a part of the Aboriginal population, did not take part in this study. When referring to health information and statistics for specific Aboriginal groups, the pertinent terminology will be used.

### Background to the Problem

Diabetes is a chronic metabolic condition resulting from total or partial deficiency in the body's production and/or utilization of insulin and characterized by high levels of blood glucose. Type 2 diabetes accounts for approximately 90% of all diabetes cases, including those among Canadian Aboriginals. Risk factors for diabetes include 1) a diet high in refined sugars, fat, and calories, 2) sedentary activity, 3) obesity, 4) age  $\geq$  40 years, 5) having a biological family member with diabetes, and 6) being a member of a high-risk population such as Aboriginal. Numerous complications are associated with diabetes including high/ low blood glucose reactions and associated diseases in the eyes, kidneys, feet, vascular system and nervous system. Though there is no cure for diabetes, complications can be prevented or delayed through healthy eating, regular physical activity, and weight management (BCPHO, 2002; Health Canada, 2002; Hjelm, Mufunda, Nambozi, & Kemp, 2003; Young, Szathmary, Evers, & Wheatley, 1990).

Reports of the diabetes prevalence rate in the Canadian population range between 4.5% (Millar & Young, 2003) and 4.8% (Health Canada, 2002), greater than the previously documented 2% (Canadian Diabetes Association [CDA], 1997; Young et al., 1990). The actual rate is estimated to be higher, as one in three persons with diabetes is unaware of their illness (CDA, 2000a; Health Canada, 2002; Millar & Young). The increase in cases of diabetes among Canadians is related to advancing population age, genetic predisposition, and most significantly lifestyles of sedentary leisure time and unbalanced diets resulting in excess weight (CDA, 2003a; Health Canada, 2002; Millar & Young). In the general Canadian population type 2 diabetes typically occurs after age 40, and men have higher prevalence of diabetes than women. Nearly half of Canadians with diabetes also have high blood pressure (Health Canada, 2002). Though people with diabetes make up an estimated 6% of the Canadian population, they account for 30 to 50% of heart attack, stroke, and new dialysis patients (CDA, 2003b) and incur medical costs that are two to five times higher than Canadians without diabetes (CDA, 2003a). Diabetes has great economic costs and places high demands on community and health care resources (CDA, 2003a; CDA, 2003b; Health Canada, 2002; Hjelm et al., 2003).

*Diabetes in Canadian Aboriginal populations*. The World Health Organization recognizes diabetes as a global epidemic that is proceeding rapidly particularly among developing countries, and minority groups and disadvantaged communities of industrialized countries. Social, cultural, economic, and political effects of

urbanization and industrialization are linked to the higher prevalence of diabetes among these populations (Hjelm et al., 2003). In Canada most reports on diabetes in Aboriginal populations pertain to Status First Nations people, however the problems of diabetes and associated complications are experienced by all Aboriginal peoples and can be inferred from the data presented in these reports (BCPHO, 2002; Health Canada, 2000). Aboriginal peoples' genetic susceptibility to diabetes makes this disease a concern for all Aboriginal people (Health Canada, 2000).

The problem of diabetes is profound in the Aboriginal population of Canada. Over the past few decades diabetes has become a leading cause of morbidity and mortality that was virtually non-existent in Canadian Aboriginal populations half a century ago. In general, rates of diabetes among Canadian Aboriginal populations are lowest in the north and in the province of British Columbia, and highest in the central Canadian provinces. Within provinces, Aboriginal people living in the south have higher rates of diabetes. However, an unexpected finding from the Aboriginal Peoples Survey (APS) is that Aboriginal people living on-reserve have highest rates of diabetes followed by those living in rural communities and lastly urban areas. Further research into the differences between on-reserve, rural, and urban Aboriginal populations' rates of diabetes and risk factors are needed (Bobet, 1998; Health Canada, 2000).

The prevalence rate of diabetes for the Aboriginal population is 2 to 5 times higher than the national average, across all age groups (Figure 1) (Bobet, 1998;





Fig. 1: Prevalence of self-reported diabetes mellitus among all Canadians (1994) and First Nations people (1991 and 1997).<sup>1</sup>

A study of the 1991 APS data found the age adjusted prevalence among the Métis of Manitoba, Saskatchewan, and Alberta to be 9% and among First Nations 11%; these rates are at least three times the western Canadian general population rate of 3%

<sup>&</sup>lt;sup>1</sup> From "Type 2 diabetes mellitus in Canada's First Nations: Status of an epidemic in progress," by Young, T. K., Reading, J., Elias, B., & O'Neil, J. D., 2000, *Canadian Medical Association Journal*, *163*, p. 563. Copyright 2000 by the Canadian Medical Association. Reprinted with permission of the author (Appendix A).

(Bruce, 2000a). Young and colleagues' (2000) study of the 1997 First Nations and Inuit Regional Health Survey (FNIRHS) found the age-adjusted diabetes prevalence rates of First Nations men and women to be 3.6 and 5.3 times higher respectively than men and women of the Canadian population. Overall the diabetes prevalence rates for all age groups of First Nations people from the FNIRHS are 20% greater than those from the Aboriginal Peoples Survey (Health Canada, 2000).

Significant numbers of new diabetes cases identified by community wide screening studies indicate that rates of diabetes in First Nations populations are on the rise and "diagnosed cases do not represent the total burden of disease" (Young et al., 2000, p. 562). Continuous surveillance studies have allowed researchers to conclude increasing prevalence of diabetes in First Nations populations cannot be fully explained by improved access to health services or screening practices alone (Fox, Harris, & Whalen-Brough, 1994; Harris et al., 1997; Young et al., 2000).

Though the age group most affected by type 2 diabetes is 65 years and older, the disease generally affects Aboriginal people at a younger age than the non-Aboriginal population, and is increasingly observed in Aboriginal children and adolescents. In the Aboriginal population, women are at least twice as likely to be diagnosed as men (Bobet, 1998; Health Canada, 2000; Young, 1993; Young et al., 2000). Aboriginal people with diabetes experience higher rates of hypertension, heart disease, renal disease, and vision problems than Aboriginal persons without diabetes (Bobet; Bruce, 2000b; Waldram et al., 1995; Young et al., 2000) and higher

rates of these complications compared to non-Aboriginal people with diabetes (BCPHO, 2002; Bobet; Daniel et al., 1999; Health Canada, 2000). Poor blood glucose control is reportedly high among Aboriginal people with diabetes (Fox et al., 1994; Young et al., 2000) as are short term and long term complications of diabetes (Bobet; Fuller, 1991; Young et al., 2000). An Aboriginal person's risk of death due to diabetes is much higher than that for the non-Aboriginal Canadian (Bobet; Fox et al.; Health Canada, 2000; Young et al., 2000).

Researchers agree that a combination of genetic factors and change from traditional Aboriginal lifestyle to modern ways of living are connected with the high susceptibility of Aboriginal people to diabetes. Limited physical activity and a diet high in calories, saturated fat and simple sugars are related to the risk factor obesity, and are suspected in the marked variation in diabetes in Aboriginal populations (BCPHO, 2002; Bobet, 1998; Bruce, 2000a; Daniel & Gamble, 1995; Health Canada, 2000; Young et al., 2000; Young, 1994). Diabetes prevalence among Aboriginal peoples is exacerbated by the poverty, low education levels, unemployment, and other socioeconomic conditions that often characterize the marginalized position Aboriginal people have within Canadian society (Daniel & Gamble; Gregory et al., 1999; Travers, 1997; Waldram et al., 1995). These conditions make it more difficult to adopt healthy behaviours by limiting access to healthy food and recreational opportunities, lowering self-esteem necessary to make healthy choices (AHABC, 1999; Bobet; Health Canada, 2002; RCAP, 1996), and

contributing to inequities in access to health care services (BCPHO; Bobet; RCAP, 1996). The relationship between socioeconomics and diabetes is discussed in more detail in Chapter Two.

Diabetes in British Columbia Aboriginal populations. Most statistics about diabetes among Aboriginal people in British Columbia are limited to status First Nations people. Generally lower prevalence of diabetes is observed among Aboriginal people in British Columbia than Aboriginal people elsewhere in Canada. However, the rates of diabetes among Aboriginal people in B.C. are steadily and significantly increasing. In many areas the prevalence of diabetes in the Aboriginal population of B.C. exceeds that of the general population. Higher rates of diabetes for B.C. First Nations people are observed in southern areas, similar to findings across Canada, but also in coastal communities. Poor blood glucose control and high complication rates are common (BCPHO, 2002; Johnson, Martin, & Sarin, 2002; Martin, 1995; Martin & Yidegiligne, 1998). Young et al. (1990) reported that in 1987 the age-adjusted prevalence rates of diabetes were 1.4% for males and 1.8% for females in the status First Nations population of British Columbia. Martin reported an increase in the rate of diabetes among B.C. status First Nations people over five years. The overall diabetes prevalence rates for B.C. status First Nations people in 1987 were 1.14% for males and 1.70% for females; in 1992 the rates had increased to 2.47% for males and 3.33% for females. A follow-up study found these rates continue to increase considerably (Martin & Yidegiligne). According to the

1991 Aboriginal Peoples Survey 9.9% of the Aboriginal people of British Columbia had diabetes compared to 3.1% of other British Columbians (BCPHO). Age standardized mortality rates for diabetes for B.C. status First Nations people for the years 1991-2001 were 2.8 for males and 2.4 for females, compared with 1.6 and 1.1 respectively for other residents in B.C. (British Columbia Vital Statistics [BCVS], 2002). The observed increases in diabetes among Aboriginal people in B.C. are consistent with the rising number of Aboriginal people developing this disease elsewhere in Canada over the past few years (Gamble, 1993; Martin & Yidegiligne).

Aboriginal people's diabetes experience. Overall, Aboriginal people in Canada, including those in British Columbia, see the health of their people as poor and have high levels of concern about diabetes (BCFNRHS, 2000; Bobet, 1998; RCAP, 1996). Whereas in the general Canadian population, people with diabetes are less likely to perceive their health to be good compared to people without diabetes (Health Canada, 2002), there appears an even greater discrepancy in self-reports of health between Aboriginal people with and without diabetes (Bobet). The problems of diabetes and associated complications in Canadian Aboriginal communities are characterized by higher exposure to risk factors, higher prevalence rates of diabetes and complications than the non-Aboriginal population, earlier onset, and late detection or diagnosis leading to greater severity (Bobet; Health Canada, 2000). There is great need for diabetes prevention and intervention programs in Aboriginal communities. "Most Aboriginal communities are aware that diabetes is a serious health issue, but it can be a challenge to tackle this growing problem when there are so many other pressing health and social concerns" (BCPHO, 2002, p. 105).

Though better health care services targeting chronic disease management are needed for all Canadians, particularly as the population ages (BCPHO, 2002), the Aboriginal population of Canada has unique needs specific to diabetes care. The Aboriginal population already experiences inequities in health, social status, and access to health services when compared to the general Canadian population (BCPHO). Due to the young age, demographics and rapid growth rate of the Canadian Aboriginal population, Aboriginal people, their families and communities will need diabetes prevention and care programs that differ from those of the Canadian population where health services will cater more to older age groups (AHABC, 1999; BCPHO; Health Canada, 2003). Further, with approximately half of the Aboriginal population of B.C. living off reserve and/or in urban areas (AHABC) and increasing movement of Aboriginal peoples to live in more urban areas (Health Canada, 2003; RCAP, 1996; Wilson & Rosenberg, 2002), the full extent of demand for suitable diabetes health programs for Aboriginal people in urban settings has yet to be observed.

For health services to be effective in improving the health of Aboriginal people there needs to be recognition of Aboriginal people's health issues and challenges. It has been argued Aboriginal people must be included in the planning and operations of health services so that programs are based on cultural concepts of

health and address communities' needs (RCAP, 1996). The Royal Commission on Aboriginal Peoples (1996) emphasized the importance of documenting and examining the perspectives and experiences of Aboriginal peoples. Research focused on Aboriginal health is needed to document disparities and to support the development of health programs.

### Community Profile

In Prince George, British Columbia, Aboriginal people make up approximately 17% of the population (Bryant, 1999). Status First Nations residents represent just over half of this value, 8.7% of the population of the area, compared to that province wide of 3.8% (BCVS, 2002). The socioeconomic characteristics of the Northern Interior Health Service Delivery Area (NIHSDA), which includes Prince George, when compared to other regions in the province of British Columbia depict higher unemployment rates, a higher proportion of the population on income assistance, and a higher proportion of the population with less than a high school education (Bryant; British Columbia, 1995). Throughout the province the standard of living for an Aboriginal people living in the Northern Interior have better health status than Aboriginal people living in the Northern Interior have better health status than Aboriginal people living in the Northern Interior. By comparison non-Aboriginal residents of the Northern Interior have lower health status than residents in the southern part of the province (BCPHO). In the NIHSDA the prevalence of diabetes is slightly higher than the overall provincial rate (BCVS, 2002). The CDA (2000b) estimated 3.9 % of the general population in the NIHSDA had diabetes in the year 2000. Age standardized mortality rates for diabetes for status First Nations people of the NIHSDA for the years 1991-2001 were 1.5 %, compared with 1.9 % for other residents (BCVS). Prevalence rates of diabetes for the Aboriginal population of the Northern Interior Health Service Delivery Area, and more specifically Prince George, do not exist. *Study Purpose* 

The purpose of this study was to document the views of urban Aboriginal people regarding their diabetes, suitable health care, diabetes education, and support services. It is hoped this study will benefit the Aboriginal people in Prince George by giving them the opportunity to share their point of view, expectations, feelings, and experiences about: a) their diabetes, b) diabetes care services, and c) what diabetes health education and support services they feel would be helpful to urban Aboriginal people in Prince George. Such research will increase awareness of Aboriginal people's experiences of diabetes and help health care providers and agencies in the Prince George area engage with Aboriginal people to plan for better diabetes care programs in Prince George.

#### **Research** Question

The initial research question proposed for this study was, "What are the perspectives of urban Aboriginal people with diabetes regarding appropriate diabetes health education and support services?" However, during the interviews and process of data analysis I came to an understanding that health education and support services were encompassed by the broader term 'health services'. Medical care, patient-education, and support services are integral parts of quality health services. Patient education, in this case diabetes education, refers to information provided by a doctor, or other health professional, about the nature of the patient's disease and health management. Therefore, for the purpose of this thesis the research question is more appropriately written, "What are the perspectives of urban Aboriginal people with diabetes regarding appropriate health services?"

### Framework of the Thesis

Presented in Chapter Two is a discussion of the literature addressing Aboriginal people's perspectives about diabetes, urban Aboriginal people's experiences of health services and diabetes care. Discussed are the problems associated with the conventional diabetes care model. New approaches to chronic disease care, specifically collaborative care and self-management education are introduced. Discussed in Chapter Three is the methodology used in this study. The findings, reflecting on participants' perceptions of diabetes and health services, are presented in Chapter Four. Finally, the results of the study as they relate to the literature are discussed in Chapter Five, and self-management education is explored as a framework to address the diabetes care and education needs identified in this study.

#### Chapter 2: Literature Review

Research on Aboriginal people's experiences of diabetes predominantly has taken place in reserve and rural communities, while literature on urban Aboriginal people's perspectives about diabetes and experiences using health services is limited to a few studies. To create a context for this study, topics examined in this chapter are drawn from a combination of this general body of literature. Notwithstanding cultural variability among Aboriginal people, their perceptions of diabetes and the ways in which illness is understood tend to be similar. Generally, Aboriginal people's practices of caring for their health and use of health services are reflective of their cultural and socio-economic circumstances.

The following review of literature is organized into four topic sections. After first discussing the literature pertaining to the general perspectives about diabetes of Aboriginal people in Canada, the urban Aboriginal experience of using the Canadian health system will be described. The next section provides an explanation of conventional diabetes care services and reasons for the lack of effectiveness in the Aboriginal population. The latter part of this literature review will talk about the new paradigm of chronic disease management, emphasizing self-management. *Aboriginal Perspectives About Diabetes* 

In a generalized view of Aboriginal concepts of health, the health of an individual is interrelated with the health of family and community. Illness is believed to be the result of a state of imbalance (AHABC, 1999; Garro, 1995;

RCAP, 1996). Studies exploring Aboriginal people's perspectives about diabetes are consistent in finding that diabetes is thought to be the result of the transition from a traditional lifestyle to modern habits, particularly a change in diet away from traditional foods and a decrease in physical activity. Urban Aboriginal people share these beliefs (Gregory et al., 1999; Hagey, 1984; Travers, 1997). Though there is widespread understanding among Aboriginal adults with diabetes that their children could develop diabetes (Cosby & Houlden, 1995; Garro; Grams et al., 1996; Gregory et al.), a few studies found Aboriginal people have reservations about the concept of diabetes-heredity because of the short history of diabetes in Aboriginal communities (Garro; Sunday & Eyles, 2001). Due to a lack of previous collective experience of diabetes, cultural understandings and responses to diabetes are still unfolding (Waldram et al., 1995; Young, 1994).

Denial, grief, and anger are common responses for anyone diagnosed with diabetes. In general, Aboriginal people's fears relate to learning that diabetes is a life-long illness and include but are not limited to economic costs of diabetes care, developing complications, and the anticipated loss of normalcy and freedom to pursue a chosen lifestyle (Grams et al., 1996; Sunday & Eyles, 2001). Family members of the person with diabetes experience similar fears for their loved one, and many times, in attempting to be helpful, their nagging creates tension and frustration (Boston et al., 1997; Fuller, 1991; Grams et al.; Sunday & Eyles). In turn, Aboriginal people with diabetes often feel their disease isolates them from family, friends, and community. Lack of social support for persons with diabetes affects decisions to follow diabetes care plans.

Family and friends who have diabetes themselves are valuable resources and often primary sources of information. Learning about others' experiences with and progression of diabetes can have the benefit of influencing people to take steps to improve their own diabetes care (Cosby & Houlden, 1995; Fuller, 1991; Gregory et al., 1999). This, however, was not always the case. Cosby and Houlden found if a person thought they were following a diabetes regimen more closely than someone with complications, they were unlikely to make changes to improve their own diabetes care. As well, both in urban (Gregory et al.) and rural (Sunday & Eyles, 2001) communities, knowing too many people with diabetes gives the impression of normalcy, "like a natural part of aging" (Sunday & Eyles, p.644); thus supporting the belief that health decline associated with diabetes is inevitable and uncontrollable.

Generally, Aboriginal persons with diabetes reported that they had received from a health care provider some information about diabetes care but did not continually follow diet and exercise recommendations. Individuals who did not perceive their diabetes to be bothersome or a problem in need of control at all times, did not consistently heed lifestyle modifications (Boston et al., 1997; Cosby & Houlden, 1995; Gregory et al., 1999; Travers, 1997). Sunday and Eyles (2001) found participants would tolerate the diabetes therapy they had been prescribed up to the point where they perceived that the disease and associated complications were less invasive then the daily hassles of lifestyle change. Similarly, the research by Garro (1995) and Cosby and Houlden indicates that if a person felt physically better in response to medication or changes to their diet, they were more likely to try and follow their therapeutic regimen; however if change was not noticed or they felt worse the reverse was also true.

Gregory and colleagues (1999) concluded that the urban Aboriginal participants in their study did not understand the connection between diet, exercise, and prevention of the progression of their disease; "most participants came to know about their own diabetes through the progress of physical symptoms...and did not follow their diet or exercise regimens until they noticed significant body changes" (p. 108). Other researchers explain this observation differently; taking note of changes to physical symptoms is part of the process where people learn the boundaries of their disease (Fuller, 1991) or provided a yardstick for assessing the effectiveness of treatment (Garro, 1995). Generally, people's increase in physical symptoms precipitated fear of secondary complications and corresponded with better adherence to diabetes management recommendations. Further, Aboriginal people's perceptions about the seriousness of diabetes were found to be associated with the requirement of glucose-lowering oral medications and insulin (Fuller; Garro; Gregory et al.; Sunday & Eyles, 2001).

### Urban Aboriginal People's Experiences of Health Services

There is much discussion in the literature that urban Aboriginal people are high users of acute health care services but underutilize other health resources (Gregory et al., 1999; Maidman, 1981; Shestowshy, 1995; Waldram et al., 1995). Aboriginal people residing in urban settings usually have little difficulty in gaining access to acute health care services, but "primary health care services incorporating disease prevention and health promotion approaches are not easily obtained" (Shestowshy, p. 24). This is illustrated in the study by Jacobs, Blanchard, James, and Depew (2000) of per capita health care costs. These researchers found that urban status First Nations persons with diabetes, when compared to persons with diabetes from the general population, have higher health care costs linked to higher complicating conditions, the result of limited primary and secondary prevention opportunities for Aboriginal people. Other studies confirm that Aboriginal people have higher rates of hospitalization for diabetes and related illness (Health Canada, 2000; Jin, Martin, & Sarin, 2002). Statistics show that status First Nations people in British Columbia use doctors' services at rates comparable to other residents but are "three times as likely to be admitted to hospital for diabetes" (BCPHO, 2002, p. 93). The combination of high rates of diabetes among Aboriginal peoples and low rates of front-line care in doctors' offices may indicate problems of availability and access to health services (BCPHO). However, Waldram (1995) found similarities in the health services utilization patterns of Aboriginal and non-Aboriginal persons in the

city of Saskatoon. In this study, socioeconomics, especially poverty, was associated with underutilization of health services and not cultural stereotypes as are commonly assumed by health care providers.

Aboriginal people's patterns of use of different health services are in part the result of structural barriers to services access and institutional discrimination. Structural barriers refer to such issues as lack of information on availability and ways to gain access to services, communication problems and language difficulties in the absence of translation services (Shestowshy, 1995; Waldram et al., 1995). Institutional discrimination is the situation created when the operational structure or eligibility criteria of health services are not compatible with the social, economic and cultural circumstances of a client (Hagey, 1984; Maidman, 1981; Shah & Dubeski, 1993). As in non-urban settings (Daniel & Gamble, 1995; Garro, 1995) health care is often delivered to urban Aboriginal clients without consideration of their social, economic, and cultural circumstances (Gregory et al., 1999; Hagey & Buller, 1983; Shestowshy; Travers, 1997). To focus on individual's disease-specific problems does not provide comprehensive and coordinated services necessary for the provision of holistic health (RCAP, 1996).

Contemporary Aboriginal people's beliefs about using the Canadian health system have developed from a combination of personal experiences and by way of extended family members' sharing of their experiences (Waldram et al., 1995; Young, 1994). A problem is created when Aboriginal people's information on the availability of and access to health services is received primarily through social networks (Shestowsky, 1995), and the culture lacks experience and knowledge of how the system operates (AHABC, 1999; Farkas, 1984; Maidman, 1981; RCAP, 1996). Further, negative and stereotypical attitudes within the health care system have fostered intolerance towards Aboriginal people and affect the health care they receive (Browne & Fiske, 2001; Maidman; O'Neil, 1986; Shestowsky; Waldram et al.). In many case the medical care received by Aboriginal people was acute health services; primary prevention and encouragement to regularly use medical services to remain healthy has been lacking (AHABC; Waldram et al.).

Attempts by mainstream health care providers to take into account "cultural barriers to health care delivery have examined the culture of native people, not the barriers associated with the values and assumptions of the biomedical culture of the health care system" (Daniel & Gamble, 1995, p. 251). In many cases the practice styles of health care providers and resulting care are not found to be culturally sensitive. This is in part because health care providers tend to be non-Aboriginal and from socio-economic backgrounds better able to foster health and health seeking behavior. Health professionals generally lack an understanding of Aboriginal culture and socioeconomic circumstances (AHABC, 1999; BCPHO, 2002; Shestowshy, 1995; RCAP, 1996; Waldram et al., 1995).

Aboriginal people with diabetes tend to have lower education levels, and consequently lower income, than Aboriginal people without diabetes (Bobet, 1998;

Bruce, 2000b; Health Canada, 2002; Health Canada, 2003). Studies in Aboriginal communities have found that socioeconomic inadequacies relate to personal risk of health problems by limiting options for lifestyle change, and restricting a person's ability to receive health services. Difficulties encountered accessing health services include problems scheduling and keeping appointments because of such circumstances as not being able to afford a telephone, transportation costs, inability to take time off work, or to obtain help with child or elder care (BCPHO, 2002; Bobet; Maidman, 1981; RCAP, 1996; Waldram, 1995). Poor literacy, including poor reading skills and poor comprehension, is associated with low awareness of programs and access to health information on prevention, symptoms of illness associated with early diagnosis, and understanding medical condition and treatment (AHABC, 1999; Bobet; Maidman; Shestowsky, 1995). In contrast, people who have higher incomes and levels of education generally are better skilled in negotiating the health care system and obtaining health information (Booth & Hux, 2003; James, Young, Mustard, & Blanchard, 1997; Maidman; Millar & Young, 2003).

In summary, Aboriginal communities are characterized by poverty, unemployment, low levels of education, and other socioeconomic discrepancies. Aboriginal people's view for restoring health and wellbeing draws on the strengths of integrated holistic health care and community caring, responsibility, and respect for one another (RCAP, 1996). Increasing numbers of Aboriginal people are moving to urban centers in search for better employment opportunities, education, and health care, only to experience continued socioeconomic disparity. With migration to urban centers, Aboriginal people often leave behind support of family, friends, and community which have a major influence on health (Bobet, 1998; Maidman, 1981; RCAP, 1996). As repeatedly argued in the literature, the capacity of the health care system to address the needs of Aboriginal people in culturally relevant and meaningful ways must take social, economic, and cultural determinants of health into consideration.

### Diabetes Care

Conventional diabetes care incorporates diabetes or patient-education with medical management which involves the prescription of diet, exercise, weight loss, and in most cases, medication. The goals of diabetes care are to relieve symptoms, normalize blood glucose levels, and prevent worsening of the disease by averting onset or progression of complications (Hjelm et al., 2003; Redman, 2004). Hjelm and colleagues (2003) point out that key to success in diabetes care is the patient's "knowledge and awareness of the disease and learning self-care" (p. 426). In ideal situations, diabetes education is first delivered by the patient's doctor, and this includes covering the basic nature of the disease and the necessities of the patient to manage their health, those being blood glucose monitoring, diet, exercise, and medication management. This information is meant to be supplemented by diabetes education classes, generally offered as outpatient services; though the education is more comprehensive, it remains topic-driven.

Doctors, nurses and dietitians are regarded as experts in diabetes care by the public and health care community. Health care providers approach patient education and communication as opportunities to persuade the individual to follow treatment recommendations. The focus of the health care appointment tends to be on the technicalities of diabetes management and instructing the person with diabetes about what they need to do to improve glucose control. Persons with diabetes, as result, feel that their autonomy is restricted and they are being forced to give up choices in life (Anderson, 1985; Bodenheimer, Lorig, Holman, & Grumback, 2002; Wolpert & Anderson, 2001). The basis of this authoritative approach is compliance and adherence ideology. Successful diabetes management, or lack thereof, is construed to be entirely due to the patient's behavior, and fails to consider problems with the suitability of diabetes care content and delivery (Anderson; Glasgow & Anderson, 1999; Redman, 2004). Comparing conventional diabetes care to a framework for chronic disease self-management preparation, Redman states "the compliance with prescribed regimen mentality also alienated patients from their health care providers, devalued their own [self-management] skills and the necessity to experiment to attain them, and created a blame-the-victim standoff between providers and patients" (p. 2). The result of lowered self-confidence is often a decrease in the patient's motivation to learn (McLeod, 1997).

The literature indicates 60% (Redman, 2004) to 70% (McLeod, 1997) of people with diabetes have not received diabetes education. In Canada, contributing

to this problem are long wait lists for diabetes education clinic appointments (McLeod) and some doctors' failure to refer (Dufton, 1992). Further, Redman reported that it is unusual for a person to receive additional education after the basic diabetes education. Diabetes care efforts have been criticized because they in general have only a moderate effect on participants' knowledge and skills, insufficiently promote lifestyle changes, and often result in less than ideal blood glucose control (Anderson, 1985; Dufton; Redman). The majority of people with type 2 diabetes are not able to control their disease through diet and exercise alone, and "less than half of all people with type 2 diabetes achieve ideal glycemic control" (Redman, p. 172).

#### Aboriginal People's Experience of Diabetes Care.

The usual methods of diabetes care are notably less effective in the Canadian Aboriginal population than in the general population (Daniel & Gamble, 1995; Grams et al., 1996; Hagey & Buller, 1983). Reports suggest that few Aboriginal people with diabetes attend diabetes clinics or receive diabetes education (Health Association of BC, 2002; Health Canada, 2000). The assumption among many health professionals is that clients choose not to follow recommendations or attend diabetes education opportunities (HABC, 2002). Aboriginal clients are considered to be ignorant for not taking their health seriously and, as such, are blamed for their state of health (Gregory et al, 1999; Hagey & Buller). Health care providers expect Aboriginal people to conform to medical views of diabetes therapy and comply with information provided and advice given (Garro, 1995; Hagey & Buller; RCAP, 1996; Sunday & Eyles, 2001). Based on the dominant Western society values for middleclass clientele, diabetes care programs reflect the professional and social culture of the health professionals who design and deliver these services. In general, Aboriginal people report dissatisfaction with the conventional medical model for the management of diabetes for a variety of reasons, including a lack of awareness among health educators for Aboriginal ways of life, and problems with communication (Boston et al., 1997; Farkas, 1984; MacDonald, Shah, & Campbell, 1990).

The most common finding of studies exploring Aboriginal people's experiences of diabetes is that Aboriginal people feel diabetes care instructions tell them, in an authoritative way, how to life their lives. Garro (1995) and Sunday and Eyles (2001) explain that when health care providers approach diabetes care as primarily the individual's responsibility, social and emotional consequences of living with chronic disease are not addressed, and diabetes management is impaired. For example, Aboriginal people find that sticking to their diabetes care regimen, particularly their diet, is made even more challenging in social settings. To refuse food offered at social gatherings is considered impolite, and is an act which separates the Aboriginal person from Aboriginal community life. Further, the restriction of food goes against traditional Aboriginal health and illness beliefs which associate food with maintenance of health (Boston et al., 1997). Aboriginal people perceive health care providers do not appreciate the cultural significance of food offerings in social interactions, and overlook cultural food preferences and food preparations when making diabetes care recommendations (Boston, 1997; Fuller, 1991). This, and the cost of food for the diabetic diet, is of particular concern in urban settings (Gregory et al., 1999; Travers, 1997).

In general, Aboriginal people express interest in diabetes education and care that incorporates traditional knowledge, foods, and medicine (Garro, 1995; Grams et al., 1996; Sunday & Eyles, 2001). Urban Aboriginal people, despite variation in their cultural background, have a general desire to continue to learn traditional practices (Gregory et al, 1999; Hagey & Buller, 1983; Maidman, 1981; Travers, 1997). Gregory and colleagues found that some urban Aboriginal people complemented their diabetes care regimens through use of medicinal herbs and ceremony, however, other researchers (Shestowsky, 1995; Wilson & Rosenberg, 2002) point out that access to traditional healing service may be limited in the urban setting.

Several studies relate Aboriginal people's personal approaches to diabetes care to their experiences with the health care system and interactions with health care providers. Two studies (Daniel & Gamble, 1995; Hagey & Buller, 1983) found Aboriginal people often characterized health care providers as unwilling to relinquish control to clients that is necessary to negotiate a mutually agreeable understanding of the illness process and control. Hagey (1984) and Travers (1997) discovered medical attention for diabetes was attainable by urban Aboriginal people, but the services received generally did not lead to improvements in their health; some people were unaware health improvements were possible. This leads to the perception among Aboriginal people with diabetes that they are in a "'double bind' situation: encouraged to assume personal responsibility for a disease that, based on their experiences, does not respond well to professional treatment" (Gregory et al., 1999, p. 106). If Aboriginal people perceive their situation as unavoidable, and that despite efforts they will not be able to achieve a desired state of health, they may choose not to attend diabetes education or follow diabetes management guidelines (Fuller, 1991; Garro, 1995; Sunday & Eyles, 2001).

Consistent through the literature, urban Aboriginal people's experiences of communication problems with their health care providers contribute to their dissatisfaction with health services (Farkas, 1984; Gregory et al., 1999; Hagey, 1984; Maidman, 1981; Shestowsky, 1995). Health literacy issues, including the ability to read written material, comprehend oral instructions, or perform mathematical computations, add to this problem and diminish the effectiveness of services. From the perspective of the health care provider it is difficult to assess client's needs (Farkas; Schillinger et al., 2002). Aboriginal people and health care providers may use different communication styles and apply different meaning to words and phrases (Boston et al., 1997; Woolfson, Hood, Secker-Walker, & Macauley, 1995). This makes it difficult for Aboriginal people to interpret diabetes education information and translate the knowledge into usable and practical skills. Other studies confirm Aboriginal clients with health literacy difficulties often misunderstand the health information received from health care providers and lack the confidence and skills to request clarification. If these uncertainties are not addressed the client becomes discouraged and may chose to ignore diabetes care recommendations (Cosby & Houlden, 1995; Farkas; Fuller, 1991). Further, if an Aboriginal person is confused about their health care provider's instructions, they are more likely to ask for clarification from a member of their social network. In their view, advice based on the experiences of other Aboriginal people with diabetes is considered more valid than advice from health care professionals (Farkas; Fuller; Sunday & Eyles, 2001).

Cultural differences occur between health professionals' approaches to teaching and Aboriginal clients' learning styles (Boston et al., 1997; Farkas, 1984; Maidman, 1981). Patient education tends to be delivered through verbal and written information according to a predetermined time-table. In contrast Aboriginal learning traditionally "is conducted by verbal narrative and learning through example, not instruction; explanation is usually implicit and the individual finds his own understanding of events" (Farkas, p. 48).

The Okanagan Diabetes Project (Daniel et al., 1999), the Haida Gwaii study (Grams et al., 1996), and others both in rural (Boston et al., 1997; MacDonald et al., 1990) and urban (Gregory et al., 1999; Travers, 1997) settings identified that
culturally appropriate formats for presenting diabetes education include peer support groups and learning from other Aboriginal people with diabetes. Also indicated was the need for members of the Aboriginal community to be involved in the planning and operations of health programs to be delivered at the community level. The Native Diabetes Program in Toronto (Hagey, 1984; Hagey & Buller, 1983; RCAP, 1996) is a working example of a diabetes care model which promotes independent self care using combined traditional healing and interdisciplinary Western medical treatment. Members of the urban Aboriginal community and consultant health professionals are responsible for planning and operation of this collaborative community-based program. Involvement of Aboriginal people in teachings and use of cultural learning practices, such as story telling and discussion groups, foster opportunities to share information, express emotions, promote awareness, and solve problems.

## Chronic Disease Management

The conventional health care system, based on principles of acute and episodic care, is not suited to meet the ongoing clinical and education needs of patients with chronic illness such as diabetes (BC, 2003a; BC, 2003b; Institute for Healthcare Improvement (IHI), 2002a; McLeod, 1997; Redman, 2004). Patients' concerns of how to live with chronic disease are seldom addressed when health care providers' primary focus is on disease treatment (Lorig, 2003; Wolpert & Anderson, 2001). Standard approaches to medical care and patient education have been problematic

for patients with chronic disease who are responsible for day-to-day disease management decisions and who control the choices that affect their health and wellbeing (Bodenheimer et al., 2002; Glasgow & Anderson, 1999; Lorig & Holman, 2003). Further, a patient's chronic disease management involves factors other than the health care system including family, social and cultural community, and socioeconomic circumstances (Wolpert & Anderson). This has prompted interest by researchers and health care providers in new approaches to chronic disease care.

The researchers Corbin and Strauss identified three main tasks faced by people living with chronic disease (Bodenheimer et al., 2002; Lorig & Holman, 2003). The first involves medical management of the disease, such as taking medication or changing diet. Second, patients must adapt their roles in everyday life, such as with work and family. The final task is that of dealing with emotions such as anger, fear, and depression, created by coping with having a chronic disease. Assisting patients to succeed with these tasks has become the focus of chronic disease care (Bodenheimer et al.; Lorig & Holman; Redman, 2004).

Chronic disease management is a systematic approach that is proactive and emphasizes keeping people as healthy as possible. This approach is a coordinated strategy requiring the participation, collective knowledge and experience of multidisciplinary health care providers. Adaptations of the chronic care model have been successful in a variety of settings and different populations, and are now being used to redesign health service delivery systems (BC, 2003a; BC, 2003b; BC,

2004a; IHI, 2002a; Northern Health, 2004).

The chronic disease prevention and management model (Figure 2) illustrates the elements contributing to the chronic disease management approach.



Created by: Victoria Barr, Anita Dotts, Brenda Marin-Link, Darlene Ravensdale, Sylvia Robinson, Lisa Underhill (2002) \*Adapted from the Chronic Care Model: Glasgow, R., Orleans, C., Wagner, E., Curry, S., Solborg, L. Does the Chronic Care Model Serve Also as a Template for Improving Prevention? The Mibank Quarterly, 79(4), 2001. Also the World Health Organization, Health and Welfare Canada, Canadian Public Health Association. Ottawa Charter of Health Promotion. WHO, Copenhagen. 1986

Fig. 2: The chronic disease prevention and management model.<sup>2</sup>

<sup>&</sup>lt;sup>2</sup> From "The expanded chronic care model: An integration of concepts and strategies from population health promotion and the chronic care model," by Barr, V.J., Robinson, S., Marin-Link, B., Underhill, L., Dotts, A., Ravensdale, D., et al., 2003, *Hospital quarterly*, 7, p. 77. Copyright 2003 by the Longwoods Publishing Corporation. Reprinted with permission of the author (Appendix B).

The model is useful in guiding the development of actions ranging from health promotions aimed at preventing chronic disease to activities of disease management and the prevention or minimization of complications (BC, 2003a; Northern Health, 2004).

The chronic disease management approach is dynamic and encourages ongoing health system redesign which occurs through monitoring and evaluation of the client population's health and making of changes to health service delivery (Davis, 2002; IHI, 2002b). Advocates of chronic disease management maintain that the elements of this model are leading opportunities for improved health status and better health services utilization (BC, 2003b; Davis, 2002; IHI, 2002a; Lorig, 2002). Decision support gives health care providers evidence-based best practice guidelines and implementation tools to substantiate treatment decisions. Multidisciplinary health care providers and specialists share information and support in a team effort to achieve maximum success in patients' treatment and self-management. Information systems include a clinical information data registry that tracks patients so that members of a patient's care team can follow the course of treatment, generate care plan reminders, identify special needs, and monitor progress. As well, population data can be produced. A delivery system design organizes the plan for using the patient registry to ensure that patients receive the treatment and follow-up outlined in their care plans. Members of the interdisciplinary care team have assigned roles, duties and tasks to perform with patients to ensure continuity of care.

Community partners offer effective community awareness programs, selfmanagement resources, and support opportunities for chronically ill patients and their families. The model illustrates the need for health care organizations and providers to network with community organizations, promote coordination of programs and resources, and endorse community initiatives (BC, 2003b; Davis; IHI, 2002a; Lorig). Further, the community elements integrate aspects of population health promotion into the model which allows for social, environmental, and cultural factors that influence health to be addressed (Macgregor, Ravensdale, & Barr, 2002). Self-management is the key element to a person's success with chronic disease care.

Self-management. Patients of chronic disease play a central role in their health. Self-management refers to "the decisions and actions an individual takes to cope with or improve their health" (BC, 2004b, p. 1). Patients require information, assistance and support to become active and effective managers of their own health. The role of the health professional is to be a consultant to the patient; sharing expertise about disease and disease treatment while respecting patients as experts in their own lives and supporting patients in their self-management choices (BC, 2003b; Bodenheimer et al., 2002; Lorig & Holman, 2003).

In collaboration, the patient and health care provider make health care decisions together. There are four steps to this patient-centered process. In the first step, the health care provider assesses the patient's needs and asks the patient what

they perceive to be their main problems. Once problems are defined and agreed upon, the second step is to consider realistic and attainable solutions to the problems, and outline possible goals. Third, the patient and health care provider, together, develop an individualized action plan; this consists of resolutions to problems that the patient wants and feels prepared to do. The action plan guides the fourth step, follow-up: frequent evaluation and refinement of the action plan in support of the patient's self-care efforts, including supporting care from other health service providers. This approach allows patients to attempt goals of selfmanagement incrementally, and thus over time change behavior. Success at small steps over time builds the patient's confidence in their disease management (Bodenheimer et al., 2002; IHI, 2002a; Von Korff, Glasgow, & Sharpe, 2002; Von Korff, Gruman, Schaefer, Curry, & Wagner, 1997; Wolpert & Anderson, 2001).

However, some patients are likely to be accustomed and socialized to expect health care providers to diagnose illness, provide treatment and alleviate suffering (Lorig & Holman, 2003). "In order to implement collaborative care, patients and their families require access to the necessary information and services to enable them to play a full and informed role" (Von Korff, Glasgow, & Sharpe, 2002, p. 92). Self-management education helps people learn to participate in collaborative care efforts with their health care providers.

Self-management education. The goal of self-management education is to enhance patients' confidence through the development of skills and knowledge they

then can apply to be an active participants in their health and health care. At the same time participants are learning, they receive support from their peers. Self-management education is not disease-specific; the approach is applicable to people with a variety of chronic diseases yet similar health care needs. Self-management education is commonly offered in community-based settings to groups; this fosters the inclusion of family and friends. Groups are led by trained peer leaders, who themselves have a chronic illness. The group determines the content of the session, which is monitored by the leader to ensure that critical information is covered as outlined in a detailed teaching manual. The leader also ensures various self-management education topics are covered over a series of sessions (BC, 2004b; IHI, 2002b; Lorig, 2002; Lorig et al., 2001; Lorig & Holman, 2003; McGowan, 2004; Redman, 2004).

Five core self-management education skills are developed through participation in self-management education programs. The first is basic problem solving. This includes problem description, identifying possible solutions, implementing a solution, and evaluating the results. Unlike typical diabetes patienteducation where clients are given predetermined solutions to common problems that may be experienced, participants in self-management education learn the skills to troubleshoot their own unique diabetes care difficulties. The second skill is decision making. This involves building knowledge which is used to respond to daily challenges of personal disease. Third, participants are taught how to find and utilize

resources, and to seek services from several sources. For example, participants may need to learn how to use the phone book to identify resources. The fourth skill involves teaching people the responsibilities of collaborative partnerships with their health care providers. This includes understanding how to communicate their disease progress and feedback about their care regimen, and how to participate in disease management decisions. Lastly, participants learn how to make and carry out short term action plans, in steps that each participant determines are both manageable and something he/she wants to do (Bodenheimer et al., 2003; Lorig & Holman, 2003; Redman, 2004).

The effectiveness of self-management education programs is attributed to four reasons associated with increased self-efficacy (Lorig, 2003; Lorig & Holman, 2003; Redman, 2004). The first, modeling, occurs when participants learn from others' experiences. For example, when a person discloses a problem they are experiencing to the group, and the other members offer solutions based on personal experience, the person's confidence is motivated by hearing about other's relevant successes. Second, reinterpretation of symptoms by way of group members' alternative explanations for symptoms may encourage participants to consider different options of self-management. Third, social persuasion occurs when the participant is activated to set and act on new goals by the encouragement and support received from peers in the self-management education group. Lastly, skills mastery occurs

when an individual takes action and gains confidence by doing (Lorig; Lorig & Holman; Redman).

Self-management education has been found to improve health status of participants and lower health care costs to the system (Bodenheimer et al., 2002; Lorig, 2003; Lorig et al., 2001). The latter is due in part to fewer outpatient visits as patients become more autonomous in self care (Lorig et al.; Von Korff et al., 2002). Chronic disease self-management program pilot projects implemented by the University of Victoria Centre on Aging have demonstrated promising results. Six months after the program participants were better skilled at managing their symptoms and disease, were less distressed and limited by their health condition, had better communication with their doctors, and had improved health outcomes (McGowan, 2002; McGowan, 2004).

Overall, conventional diabetes care has not been effective in providing adequate care to persons with diabetes (BC, 2003a). The chronic disease management approach is relatively new to clinical practice, such that few patients have received self-management education (Bodenheimer et al., 2002) and collaborative care from their health care providers (Paterson, 2001; Redman, 2004). The development of a new strategy for diabetes care in accordance with chronic disease management initiatives and redesign of the health care system is underway (BC, 2003a; BC, 2004c; CDA, 2003c; Marin-Link, 2002; McGowan, 2004). Recently a number of chronic disease self-management program pilots have begun throughout the health authorities of British Columbia, including diabetes initiatives and programs for Aboriginal communities (BC, 2003a; McGowan, 2002; McGowan, 2004).

## Summary

Overall, the literature suggests that the health information provided to Aboriginal people is not sufficient to result in an accurate understanding of diabetes and treatment choices. Aboriginal people with diabetes are generally dissatisfied with the usual methods of diabetes care. The availability and accessibility of primary and secondary diabetes health services for Aboriginal people is an issue, even in urban settings. Aboriginal people's access to health services and difficulties adopting healthy behaviours are exacerbated by socioeconomic circumstances. Further, social, economic, and cultural factors often are not considered by health care providers in the delivery of services to Aboriginal people. There is need for better understanding of the biomedical culture of the mainstream health care system in order to better meet people's needs. Use of the chronic disease prevention and management model to restructure the health care system and delivery of chronic disease care may provide the means with which to improve diabetes care services so they positively contribute to Aboriginal people's health.

#### Chapter 3: Methods

This study used a qualitative research methodology. Qualitative research is a naturalistic, interpretive approach suited to studies that wish to describe and explain the experiences of people, understand their perspectives, and preserve their stories (Burnard, 1994; Miles & Huberman, 1994). Discussing uses for qualitative studies Miles and Huberman explain "a main task is to explicate the ways people in particular settings come to understand, account for, take action, and otherwise manage their day-to-day situations" (p. 7). This methodology fits the objectives of this study – to document the views of urban Aboriginal people regarding their diabetes and suitable health care, diabetes education, and support services. Further, the exploratory qualitative research design helped to ensure the comfort of the participants; oral methods of data collection were likely to be more meaningful and sensitive to Aboriginal people. Open-ended, in-depth interviews allowed for participants to express their understandings regarding the topic of study in their own words (Bauman & Greeenberg Adair, 1992) and helped to ensure the participants' points of views were respected and valued (Spradley, 1979). Use of interviews draws upon rich data and a complete assessment of the topic for the researcher, while avoiding problems associated with questionnaire readability. Using this method provides greater opportunity for the establishment of good rapport between the interviewer and respondent. This encourages participants' self-disclosure and avoids the influencing of the participants' reports, such that interviews may uncover information that the researcher had not anticipated (Bauman & Greenberg Adair; Miles & Huberman; Morse, 1994; Spradley).

## **Participants**

Participants, of which one was a key informant, were identified through assistance from the Central Interior Native Health Society in Prince George, British Columbia. This means of facilitating researcher access to the urban Aboriginal community was selected for appropriateness and sensitivity. The Royal Commission on Aboriginal People (1993) identified Native friendship centers and health clinics as "the primary vehicle of service delivery to Aboriginal people in urban centers" (pp. 13-14). After approval was obtained from the University of Northern British Columbia Ethics Committee and the research design was reviewed with the Director of the Central Interior Native Health Society, recruitment of participants began.

Persons eligible to participate in the study were adults (18 years of age or older) who self-identified as being urban Aboriginal (Fuller, 1991; Statistics Canada, 1991) and identify their selves as persons with type 2 diabetes (Gamble, 1993; Young et al., 1990). To ensure that participants were experienced with daily living with diabetes, and had information to share regarding their expectations for and impressions of health services, participants were sought who had been diagnosed for at least one year (Fuller; Spradley, 1979). Further, the participants were to have lived in Prince George for at least a year to ensure familiarity with services (Spradley). Participants needed to be comfortable and interested in discussing their diabetes and their health services impressions, expectations, and experiences. As well they needed to be willing to participate in two 1.5 hour (on average) tape recorded interviews with the researcher who is a graduate student from the University of Northern British Columbia.

Eight people, five females and three males, were enough to provide adequate data to serve the purpose of the study. In an exploratory qualitative study the amount of information collected is considered sufficient when the researcher is able to make sense of the research question, participants confirm their accounts, and no new information is provided (Morse & Field, 1996). Two participants were interviewed once and six participants were interviewed twice during 1998; the other two were not available for second interviews. Then in 2003 one of the six participants was interviewed a third time along with the community outreach nurse, to assess whether the findings were still current.

This study involves a total of eight participants. Six of the participants said they were Status Aboriginal and the other two described themselves as non-Status Aboriginal. They ranged in age from 44 to 74 years; the mean age was 59. Participants had been diagnosed with diabetes between the ages 33 and 53 years; the mean age at diagnosis was 44. Two participants, one divorced and the other widowed, lived alone. Two participants lived with a spouse, two lived with a spouse and children, and two were widowed each living with a son. Participants' levels of education ranged from 2 to 12 years plus adult education. All but one participant attended residential school for some or all of their education. Three participants expressed trouble with reading, writing, and some times understanding the English language. Participants' sources of income varied; three were currently employed, one received disability pension, two received seniors' pensions, and two received income assistance. Consistent with findings of other studies (Fuller, 1991) participants had many family members with diabetes. Before diagnosis only three participants had family members with diabetes, but seven of the eight participants had family members with diabetes at the time of the interviews.

A community outreach nurse was essential to the recruitment of participants. With the criteria for participation I outlined, the nurse identified appropriate individuals and made initial contact. Using an information sheet provided, the nurse explained the purpose of the study and what participation would entail with the possible participant. If the person expressed interest in the study the nurse asked for permission to provide the researcher, myself, with contact information. I then arranged interviews to take place at times convenient for participants.

The first participant recruited became a key informant to the research. This individual has experience as an Aboriginal person with diabetes, works in the health care sector, and is a prominent member of the local Aboriginal community. The key informant assisted the researcher in reviewing the wording of the interview questions for sensitivity and meaning to urban Aboriginal people with diabetes. This person was also interviewed for the study. Spradley (1979) explains that by first interviewing a key informant the researcher discovers how to ask the questions and probe for information such that the following interviews are more likely to flow freely. Borrowing from ethnographic techniques participants in the study were consulted as general informants who through the interview process teach the interviewer about the topic of study (Bauman & Greenberg Adair, 1992; Spradley, 1979). Lofland and Lofland (1995) suggest "younger researchers may be granted more leeway in this regard, since their lack of knowledge is compatible with their age" (p.40). The approach respected the traditional Aboriginal youth-as-learner, elder-as-teacher relationship, improving potential for participants to openly share their perceptions and experiences.

## Data Collection

Interviews took place in a quiet and private room at a health clinic unless another suitable location was requested and preferred by a participant. The interview locations included seven at the health clinic, three at the University, one at the College, one at a participant's home, two at a participant's place of work, and one in an outdoor park. The last location, though public, was requested by the participant who wished to enjoy the sunshine and did not often have a ride to the park. The differences in interview locations did not appear to affect participants' responses.

The participants were informed by the researcher when making appointments for the interviews that they may request to have a community outreach nurse present during the interview. The decision to offer this option was to ensure a comfortable

and trustworthy climate for the participants. Other studies have shown that having a community health worker present in the interview process strengthened the researcher's sensitivity to the participant's needs and the reliability of the information (Gamble, 1993). Rather than include the nurse in all interviews, I felt that it be important for the participants to have the choice. All declined to have the nurse present.

In-depth interviews were conducted with the participants in English, the working language of the CINHS. However, English was a second language for all but one participant. This may have created some limitations on the information received. For this reason, at times rephrasing of questions was necessary. Participants did not hesitate to ask for clarification when uncertain about a question, and interviews proceeded without problems.

General demographic information was obtained at the beginning of the first interview and served to ease the participant into the interview and establish rapport. Semi-structured open-ended interview questions (Appendix C) were used to guide the first interviews. This "structures the content of the interview" (Bauman & Greenberg Adair, 1992, p. 10), while at the same time the participants are allowed the freedom to explore the issues they consider most important. Casual interviewing techniques (Lofland & Lofland, 1995) involve use of probes, pauses, and rephrasing snippets of the participant's comments to prompt elaboration by participants. In a few circumstances participants offered prolonged silence to a question, asked for clarification, or shared information still relevant but of a different feature. At these times, based on the participant's response, questions were asked to allow for participants to clarify and broaden their comments or chose to move onto the next question. Second and third interviews were used to clarify information, request further detail, and ask questions regarding my interpretation of the data collected in the first interviews.

Interviews lasted 1 to 1.5 hours and were recorded on audio tape. I took journal notes during the interview and immediately following the interview to document participants' non-verbal reactions during the interview, my personal thoughts and observations made during the interview process. Occasionally participants added information once the interview had concluded and the tape was turned off. These data were documented in the journal notes and incorporated with the transcribed data. Note taking was primarily used to document interview improvements such as questions to go back to, ideas to probe, and rephrasing of questions for better understanding. This way my attention was predominantly on the participant, and I was not distracted by the task of taking notes (Lofland & Lofland, 1995). I transcribed all audio tapes verbatim by myself.

Following the interviews I gave participants the opportunity to add any other thoughts and ask questions. At this time I scheduled an appointment for a second interview to take place a few months later. The delay in scheduling the second interview allowed time for participants to be interviewed once before I began the

second round of interviews. It also allowed me to review the data from the first interviews. I telephoned participants two days before the second interview to confirm the appointment or make alternative arrangements if necessary. Data collection and the beginnings of analysis took place simultaneously.

# Ethical Considerations

At my first meeting with each participant, I provided written explanation of the purpose for the study (Appendix D) that included what participation entailed and the agreement of participation (Appendix E). In all cases I discussed these documents with the participant to accommodate for the possibility of low literacy level. Participants were offered time to decide whether or not to take part in the study; one participant requested this privilege. Fuller (1991) suggested that such an informal meeting between the researcher and the potential participant is sometimes needed to establish rapport and trust. In the end, all participants volunteered to take part in the study. Prior to beginning the first interview, both the participant and I signed the agreement of participation in duplicate (one copy for each person). Participants also kept their copy of the letter describing the purpose for the study. In cases of second and third interviews, these documents were discussed at the beginning of the meeting to ensure informed consent remained.

Confidentiality and anonymity for participants was assured, and has been maintained by several mechanisms. Audio tapes, journal notes, transcribed data, and working documents have been securely stored in the researcher's home office at all times. Participants were further protected by pseudonyms and changes to other details which may have drawn attention to their identities throughout working documents and this thesis. Discussion of the content of the interviews has only occurred at the level of main objectives and thematic description of the findings. All participants understood that I would write about the information they provided in my thesis. Participants expressed pleasure in the opportunity to speak about their experiences living with diabetes, and were pleased to see research focusing on Aboriginal people's interests. No one withdrew information or cut an interview short out of concern about confidentiality. At the beginning of this research it was agreed that the Central Interior Native Health Society (CINHS) would retain ownership of the primary data collected, namely the audiotapes (Appendix F). They have been provided to the CINHS.

It was recognized that the discussion of diabetes could lead to painful memories (Herbert, 1996), or uncover current health ailments. At times participants viewed the interviews as opportunity "just to talk to someone." Respectfully I accommodated them and listened. In the course of interviews some participants requested help with problems they were experiencing. Two participants said they were afraid to go to health services appointments alone. In these cases I explained they could bring a family member or friend with them to appointments for support. I later learned in follow-up interviews that both of these participants followed my suggestion which was welcomed by their health care providers. Another participant

disclosed she was experiencing high blood sugar levels and suffering uncomfortable symptoms, which she suspected to be the cause of an infection. I felt it necessary to encourage this participant to make an appointment with her doctor. Participants received no pay for participating in the interviews. In a few cases where participants had difficulty arranging transportation to or from an interview, I drove them in my personal car. All interviews proceeded smoothly.

#### Data Analysis

Thematic content analysis was used to analyze the data. This is an objective and systematic process of arranging descriptive data into categories on the basis of similarities and differences that reflect the research question (Burnard, 1994; Guba & Lincoln, 1981; Holsti, 1969; Krippendorff, 1980; Pope, Ziebland, & Mays, 2000). Analysis was inductive - categories "emerge from the material itself rather than be imposed *a priori* by a theoretical construct" (Guba & Lincoln, p. 240). After completing the initial interviews the thematic template used to organize the data was developed from natural groupings of information in the data. Written interpretation of the categories then allow for comparison with literature and the theoretical relevance of the information to be communicated to others (Burnard; Guba & Lincoln; Pope et al.).

Initially, I began the analysis by reading the transcripts a number of times to identify persistent themes. Notes were penciled into the margins to record my thoughts and make connective links to similarities and differences. I then duplicated copies of the transcripts and created an index card for each, and all, of the statements and interesting stories made by the participants that reflected in some way the themes that were developing in relation to the research question. By the process of constant comparison (Pope et al., 2000) I reviewed and filed the index cards several times until broad categories were constructed, for example "coming to diagnosis." Created from the similarities and differences identified within the broad categories were subcategories such as "body changes," "attending to changes," and "personal awareness of diabetes." The final thematic template is represented by the headings in Chapter 4. A complete copy of the interview transcripts was always on hand to review the greater context from which the vignettes originated. Pope and colleagues explain this, albeit somewhat old fashioned paper system, "can help the researcher to develop an intimate knowledge of the data" (p. 115). To ensure the categories were mutually exclusive and accounted for all data (Burnard, 1994; Guba & Lincoln, 1981; Pope et al.), I used the thematic template of categories and subcategories, and compared the complete data from each transcript to the themes for a logical fit (Burnard; Travers, 1997). From the categories of arranged data, a rich description of the findings was written to display the participants' collective story. Minimal interpretation is offered so as not to lose the participants' voices. Using extracts from the interviews helps to illustrate the nature of participants' experiences and perspectives.

Reliability and validity. Morse (1994) explains the major methods of ensuring rigor in qualitative work "are intricately linked with reliability and validity checks" (p. 230). This was achieved by strict commitment to the methodology outlined. The procedures of data collection ensured adequacy and appropriateness (Morse). Careful documentation of the decisions required of data analysis contributed to the auditability of the methods. In qualitative research validity refers to the study's ability to truly reflect the events as they exist in a natural setting and the meaning of participants' experiences (Bernard, 1994; Morse). As the early stages of data analysis occur during data collection, second interviews allow participants the opportunity to clarify whether or not the researcher is interpreting the information already gathered in a way the participants intended (Pope et al., 2000). One difficulty encountered in the study was that interpretation and analysis of the data was not completed until after the second interviews. To assess whether my findings were valid I discussed my interpretations with the key informant and the outreach nurse. Though this process occurred while I was still in the process of writing it allowed me to verify the main themes and decisions I had made regarding similarities and differences in the information participants had provided. Reviewing the findings with the community outreach nurse allowed for verification of whether the interpretations I was making resonate with the experiences of Aboriginal clients with diabetes known to her. A further check of validity occurred when I tested the fit of the categories to the data (Burnard; Travers, 1997). Appropriate interpretation of

the data is evident in the clarity of the written results, where the flow makes sense, and quotes of participants' words are reflective of the line of reasoning presented. *Summary* 

It is hoped that a rich description of the perspectives and experiences of urban Aboriginal people with diabetes about health services will help to find ways of offering meaningful and sensitive health programs to this population of the community. Presented in the following chapter are the findings of this study. The goal is for urban Aboriginal people to be able to identify with this work and that health professionals will use it as a guiding document in the development and ratification of health resources and services. Chapter 4: Participants' Experience with Diabetes and Health Services

Few studies have explored the experiences of urban Aboriginal peoples with diabetes. As discussed in Chapter 2, urban Aboriginal people predominantly consult acute health services for their diabetes care, despite the availability of diabetes education clinics and community services committed to diabetes. This study was designed to find answers from Aboriginal peoples about their perspectives on diabetes and their experiences using health services. Participants were asked about how they experienced their coming to diagnosis and what it was like to take care of their diabetes. The participants described challenges from the time before they knew of their illness to daily life with diabetes and managing self-care.

## Coming to Diagnosis

It is essential to understand participants' perceptions of the events leading up to their diagnosis in order to grasp their experiences with diabetes. Body changes were participants' first sign of wavering health. Participants relied on self-evaluation of their health to determine whether they should see a doctor. Two common approaches were evident in the interview transcripts. First participants did not visit the doctor unless they thought they were sick. Second participants were afraid of what a doctor might say about their symptoms and so were reluctant to go. Participants, in most circumstances, delayed seeing a doctor until their symptoms became unbearable and interfered with their daily lives. Family members and friends served as resource networks during this difficult time and in a few cases prompted the participant to see a doctor. All participants underwent similar diagnostic procedures at a doctor's office. Participants' experiences of coming to diagnosis contributed to their perceptions about diabetes, their understanding that diabetes is controllable, and their knowledge of health resources available to assist them with their diabetes care.

*Body changes*. All participants emphasized the insidious onset of body changes when asked to recall the time they learned they had diabetes. Participants said that in the very beginning they were uncertain about the change occurring to their health. They made comments such as, "I didn't know what was going on...I didn't know that I had diabetes." Participants initially noticed an alteration to their sense of well-being. Scott<sup>3</sup> mentioned not feeling like himself.

When diabetes set into me, I didn't know the symptoms....I really didn't pay attention....I showed all the symptoms of being a diabetic, but I didn't realize....You know something is wrong with you, but you just don't know what.

Change in participants' bodies was the first tangible indication something was unusual. They describe feeling dizzy, tired, nauseous, thirsty, and cravings for sugary foods. Alone these disturbances did not cause alarm. Participants expected such indispositions to be short term. Most participants had not understood that collectively these symptoms are signs of failing health. They intervened with their own remedies before realizing their need for medical help. Marie described such a

<sup>&</sup>lt;sup>3</sup> Pseudonyms and gender variation have been used to protect the identity of participants.

situation.

I ran into this problem of being thirsty all the time. I was drinking lots of water. I remember going to A&W and ordering those big 64 ounce mugs and I would drink that right down just to quench my thirst.

Marie assumed that being thirsty was from not drinking enough. Participants interpreted the initial changes as a signal their body needed fluids, sleep, or food. Beth recalled intense cravings. "I was craving for sweets...I couldn't have enough." Similarly, many others indulged their appetites for sugary foods. These participants did not suspect illness was the cause of their constant and unusual desires.

Few participants understood what was contributing to their bodies' changes and demands. Karen's story is consistent with this progression of events. Although fatigued by exacerbating problems she did not consider medical attention to be needed at first.

I couldn't do nothing but sleep. I get up, cook and then I was tired and I have to sleep after it so I can do dishes. That's how tired I was. I was just strung right out....It was like that for quite a while before I went and seen the doctor.

This went on for two years. Seven of the eight participants lived with unpleasant diabetes associated symptoms for time frames ranging from a few months to years before diagnosis.

What was unclear to participants during the early stages of their bodies' changes was their need for medical intervention. Scott said that to have any one symptom was nothing; it was easily excused at the time as "just an everyday thing." The majority of participants were unaware of diabetes as an illness and unmindful that their body changes were signs of permanent health change. Participants, with the exception of Ken, did not immediately attend to their body changes.

Attending to changes: Community awareness of diabetes. Seven participants at first dismissed changes they experienced as a reason to go see a doctor. Participants said they became concerned about the persistence of their body changes, but they had hoped with more time their ailments would "go away." They were afraid because they "didn't understand the symptoms or the sickness." Participants said lack of diabetes awareness continues to be a problem for the Aboriginal community. Ken explains more campaigns targeting this problem are needed. "A lot of the people, they wouldn't even think to get tested. You don't know when you have it and don't feel different....There is not enough advertising in the community to make [people] aware." Participants talked about both the lack of understanding of the symptoms of diabetes by the Aboriginal community and Aboriginal people's lack of awareness of the need to see a doctor for a health check-up. Scott expressed concern for persons unable to identify body changes as signs of ill health.

They spend all of their life as a diabetic, but never bothered to look after it. They have spent all of their lives in the dark. Wondering why they act this way, act that way, because they never bother to check out, have themselves diagnosed with whether they are a diabetic or not.

Participants acknowledged an awareness of undiagnosed cases of diabetes in the Aboriginal community. Pam explains that further to the problem of diabetes awareness in the Aboriginal community, Aboriginal people underestimate their risk for diabetes. They seem to think that they will never catch a disease. It is because nobody ever talks about it....It is a big thing today, diabetes among Aboriginal people....They don't seem to come forward and admit they have diabetes....So people really don't make the connection.

The implication is that diabetes awareness campaigns do not personalize the disease by emphasizing the risks and symptoms people are not able to see. Participants said people with diabetes are afraid "of being criticised," and for that reason do not talk with others about their experience with diabetes. Scott points out that people with diabetes are blamed for their illness. "The people I know most won't announce that they are diabetics....They try not to look like fools." Ken speaks from experience. "If you don't tell anyone, it is only you who knows...so they don't look down upon you, but also so you are not treated differently." This line of thinking illustrates poor knowledge of diabetes at individual and community levels. It also reflects cultural values of fitting in.

Participants' statements allude to the possibility that Aboriginal people prefer to know that their symptoms warrant treatment before going to a doctor. Scott said he knew something was wrong with his health, but he "really didn't pay attention." He was "curious to know if he had diabetes," but had "no place to go to learn about diabetes without being referred by a doctor." Scott labeled this scenario "a Catch 22." He did not want to see a doctor without knowing "what [he] was getting into."

I have been hearing about diabetics and diabetes for 20 or 30 years or more. I didn't know what it was. I didn't know how a person became diabetic. I didn't know if there was a cure. I didn't know the symptoms. Mostly it was just a lack of knowledge.

Scott was afraid of what the doctor might say. Diabetes was an unfamiliar illness without a known cure. He said his lack of knowledge prevented him from seeing a doctor right away. The experience of Pam and Marie support the finding that people like to find out if they have diabetes before going to the doctor; people come to them for advice and ask to "get checked out." This placed these participants in the difficult position of having to inform someone "You need to see a doctor."

*Personal awareness of diabetes.* Participants' awareness of diabetes as an illness before diagnosis was a factor in their identification of body changes and prompted their decision to see a doctor. Having a family member with diabetes made participants familiar with the disease but not necessarily attuned to the possibility they may develop the condition. This is evident in Pam's story. "My mother had it, so I kind of knew a bit about diabetes...but I thought I would never get it." Participants with a general awareness of diabetes gave no indication of making changes to their lifestyles in order to prevent diabetes. Only Ken participated in screening for early detection.

My grandmother was diagnosed with diabetes and my brother was also....I wanted to be tested on a regular basis....I had been asking faithfully for approximately 10 years....I would have it done yearly because of the history of our family.

Ken's knowledge about diabetes was initially learned from family members' shared experiences. He had incentive to monitor his health, and to pay attention to diabetes awareness promotions, such as "the ads on the TV."

Family members with diabetes provided Scott with support for his concerns

about unrelenting body changes. Scott said he knew something was wrong with his body; changes including "kidneys fill up faster, muscle cramps, being tired and lacking energy more often than not." He dismissed these body changes because he wanted to know more before going to a doctor. Scott went to visit his family upon learning of his mother's and sisters' diagnoses.

I explained to them I wanted to be checked out for sugar diabetes. They questioned me about it. They asked me to describe the symptoms I had. And I told them, "I don't know what kind of symptoms you are looking at, but I will explain to you what I am going through." And I did, and they said, "That is the early warnings of sugar diabetes."

Scott said his body changes accounted for many of the symptoms of diabetes that his family described to him. He went to a doctor and asked to be tested for diabetes. In all the above three cases, information from family members about diabetes supported the participants' decisions to see a doctor.

Beth, Marie, Karen, Laura, and Ann all lacked personal acquaintances with diabetes at the time of their diagnoses. Karen's situation illustrates the impact of this factor on her diabetes awareness. "I heard about it, but I didn't think that I would get it. I don't think I would have known because none of my family had it." Karen's lack of family members with diabetes meant that she did not learn about the disease through family discussions. Karen "[does not] know how to write or read much," and said she never learned about diabetes via the newspaper, pamphlets, or other written forms of diabetes education. Marie "heard about diabetes but didn't know anyone who was." She explained that had there been somebody "around that [she] knew with diabetes, as an example" she may have made the connection between her body changes and signs of being sick. Beth, Laura, and Ann were in similar situations, however they had never heard of diabetes. The trigger for these five participants to seek medical advice did not occur until they were no longer able to tolerate the changes in their body, and their declining health resulted in problems affecting their capacity to perform activities of daily life.

*Seeking help.* Participants were conflicted as to how to remedy their situations and were reluctant to disclose their discomforts. Many were not accustomed to using health services and based their decisions to see doctors on their prior health care experiences, and on what information was known to them about experiences of family members and friends. Karen's story provides an example.

Karen knew she was unwell. She felt alone and was unaware that other people experienced similar health concerns. She said she did not have the resources to determine what to do.

Other diabetics, they don't know who to go to. Like me, I was all by myself for a couple of years before I found out. I know that I wasn't feeling good, I know that there was something wrong, but I didn't know what it was.

Karen found she was no longer able to take care of herself or her home because of

her body changes. Her poor state of health was noticeable to others by this time.

A friend of mine came to visit me and she asked me, "How come you are so tired all the time?" I said, "I don't know and I just get the shakes like nothing." She told me, "I am a diabetic, and you sure sound like you are one, go see your doctor." I did. Karen went to see a doctor at the urging of her friend. She had previously been afraid to find out what was causing her to be ill and was reluctant to go. "I just wish I would have seen the doctor sooner. If I knew those things, I would have went and seen the doctor right away." In hindsight Karen expressed regret for her delay.

Some participants said they were reluctant to see a doctor about their body changes because they could not afford to; either they did not have medical insurance, did not have transportation, or were concerned about the costs, such as for medication, associated with being inflicted by chronic illness. Participants with financial constraints during the time of their developing symptoms said they tried to ignore their discomforts. Marie only considered seeing a doctor about her body changes when advised to do so by a colleague. "My co-worker was the one who told me to go see the doctor because she was worried about me." Marie spent her childhood years living by traditional means on the Prairies. Her family was poor and could not afford doctor services. She said that, as a result of her upbringing, she "didn't pay much mind to doctors," and was unfamiliar with going to the doctor. Marie, on a tight budget, had not paid for her medical insurance as a young adult. She was not able to see a doctor until she could afford to have her medical insurance reinstated. Ann, like Marie, initially could not afford to see the doctor. "My medical ran out and I never paid for it right away because I was only working part time." Life circumstances caused Ann to take over a year to re-establish the medical insurance she needed before seeing a doctor. These participants are non-status

Aboriginal persons and must pay for their medical premiums like most other residents of British Columbia. They, like many people, did not pay their premiums. Other participants said "it is not uncommon" for Aboriginal people not to have medical insurance or to be "scared of diabetes because they look at the expense." Tolerating discomforts or denying one's symptoms may be a learned personal health practice.

Prior experiences with the health system. Participants said being uncomfortable with going to the doctor was one reason they delayed doing so until absolutely necessary. Marie said simply, "People don't like doctors." Many participants spoke of events that they or others had experienced that depict discrimination. Fear of being emotionally vulnerable outweighs the potential of receiving help for their health condition for people who have been demoralized during past experiences with health services. Pam talked about her concern for Aboriginal people who suffer discomforts and disabilities rather than seek medical attention. "Our people stay away from hospitals. You know they don't want to be turned away." Pam explains, the individual "loses their trust for doctors" and feels their "pride has been taken" when refused treatment. Pam said Aboriginal people continue to face discrimination in the health care system, and for this reason there is a tendency for some Aboriginal people to avoid going to doctors or other health services, "because they fear the same thing will happen to them."

I don't even like going myself because of stuff that has happened....I was really suffering there, and I just walked away. I just said, "Forget it;

I don't have to put up with this."...It is minorities, not only to Aboriginal people but to minorities.

She is at times reluctant to go to the doctor or hospital herself having undergone such "degrading experiences."

Misdiagnosis was another form of discrimination participants expressed concerns about. A fear of the health system has risen for Scott from hearing such stories.

I prefer people to know that I am a diabetic because...if they see me go into a coma or faint...somebody who can give paramedics the answers they need "he's a diabetic" so that they treat me right....Whether it's a paramedic or the doctor or a nurse, they may not recognise the symptoms of diabetes and they could misdiagnose you. That's more or less what I am worried.

Scott's fear of health professionals misdiagnosing hypoglycaemia as alcoholism is a very common reality for Aboriginal persons with diabetes (Kwan, 2003; S. Thiessen, personal communication, July 24, 2003). Having others aware of his illness provides Scott with a sense of security were he to have an acute health problem and be unable to communicate with health care providers.

Problematic experiences influenced participants' perceptions regarding future use of other health services. Negative memories and unsatisfactory care were deterrents to the participants' attention to health care needs. Laura's experience provides the best example.

Laura said she "wasn't feeling good for the longest time" but did not see a doctor right away because she lived in a rural community without doctors' services and a 1.5 hour drive from the nearest hospital, and the closest doctor. Her personal practice was to go to the doctor only when absolutely necessary. Laura's signs of illness escalated from nausea to include "convulsions" before she went to the emergency department at the nearest hospital. The emergency department staff was unable to tell her what was making her ill: "They didn't say anything about my diabetes. They didn't know....They didn't find out I was diabetic." Two months later Laura and her husband moved to an urban center. Her symptoms worsened, and still Laura refrained from going to a doctor because she did not think anything could be done to help her.

I got really sick....One morning my sister phoned me and I was talking away, but not sensible at all. She said to me, "Are you okay?" and I said, "Yeah," but I wasn't okay. I don't even know how to describe it.

Laura said her health had deteriorated to the point where she no longer knew what she was doing. "I was walking back and forth. I couldn't keep still. I was talking away about nothing." Her sister and husband recognized Laura's urgent health crisis and took her to the emergency department of a second hospital. "Right away the doctor knew that I was a diabetic. My sugar was high....They did blood tests and I found out the next day that I was diabetic."

Laura, given the symptoms she presented, should have received a thorough medical history, physical examination, and appropriate blood tests upon her first visit to an emergency department. The result would have been earlier diagnosis and avoidance of disability, discomfort, and depression. Laura's deteriorating health was not recognized when she first went to the hospital emergency department. She no longer perceived these persistent, worsening symptoms as legitimate reasons to go to the doctor. Experiences like Laura's deplete Aboriginal people's confidence in the health system and reinforce behavior of delaying seeking medical advice until crisis stage. Aboriginal people, unless presenting a critical health problem, perceive they will be turned away by health care providers. This contributes to the practice of crisis-oriented health care; visiting the emergency department of a hospital for conditions that if addressed earlier, may possibly have been addressed in a doctor's clinic.

*Experience of diagnosis.* Participants' dates of diagnosis occurred over a 25 year span; the first was in 1971 and the most recent was in 1995. Participants, with one exception who was diagnosed in the 1990s, did not indicate having been encouraged to be appropriately screened as people at risk of diabetes at an earlier date; only when participants reported symptoms and/or concerns were they tested. All participants went to see a doctor about their health troubles. They received blood glucose tests to confirm their diagnosis.

The procedure for diagnosis was similar for all participants. A number of participants said they felt uncomfortable due to the lack of information provided. They did not recall verbal explanation and opportunity for clarification regarding the diagnosis procedure. Scott and Ken best describe their experience of the procedure for the blood glucose tests. Ken recalls one of the first times he was tested for
diabetes. "I didn't understand at that time....I remember going down and having to take my blood, then staying at home, and then having to go back down again." Scott's experience is similar.

They just told me to come in at a certain time....There is no eating or drinking after midnight. You show up, they drain some blood out of you and then say come back in a couple of hours....Certain things I have no control over....They say you have to do a test then go away and do something else, and then come back for another test. That takes up a whole day, and to me that is a day of work that I have lost....They keep telling you, "you got to wait, you got to wait!"...Three, three tests in the one day....Mostly it was lack of knowledge on my part....I didn't know the procedures and I didn't know anything about being a diabetic....Plus the taking of blood, you get some bad experiences.

Scott found the diagnosis procedure unexpectedly time consuming. He said his lack of control over the situation and absence of information regarding diabetes and the protocol for diagnosis was particularly demoralizing. This experience was typical of the diagnosis process, though not all participants' experiences were as burdensome. Many participants said they were "scared," particularly of "the needle," or frustrated by having "no control" over the timing for the lab work to be done and subsequent interference with their schedules. Participants were notified of their diabetes diagnosis directly by their doctor, but the information participants received about diabetes and the management of their illness varied.

## Taking Control

The process by which participants began taking control of their diabetes reflected their individual experiences of coming to diagnosis and their beliefs about their illness. Participants said their first challenge was accepting their diagnosis. Many found this difficult because they did not understand the cause of diabetes, "how a person gets diabetes." They said the common understanding was diabetes or "Sugar Sickness" was "something to do with eating too much sugar." Participants required time to emotionally adjust to the news of their illness. Scott expressed his frustration.

How did I become a diabetic? This is the part I couldn't understand. Even to this day I am wondering how I became a diabetic. They have explained how a person is diagnosed as a diabetic....They say, "You're a diabetic."...Somewhere in the explanation is how you became a diabetic....When they explain...it seems...contradictory....They say that there is no cure...they say that there is people out there who recover from diabetes....How can that be if there is no cure?

Scott feels unconfident not having all the answers about his illness. Other participants said they were confused and shocked to have diabetes because they had not understood they were at risk. Pam explained that while her mother had diabetes, she was "in denial," thinking that she "was too young to get a disease like that." Participants without diabetic family members had assumed they would not get diabetes. Ann said, "I don't really know where it started from; no one else in my family had it." Now aware that "diabetes runs in families," many participants were scared their children and grandchildren may develop the disease. Participants were taken aback by the number of Aboriginal people with diabetes, having known few, if any, personal acquaintances with diabetes at diagnosis.

Participants said the fear they experienced around the time of diagnosis was the product of not knowing what was going on or how they would care for their health. Ken explains such feelings are part of the process of accepting the news of diabetes diagnosis. "Emotionally diabetes is just like being diagnosed with cancer or MS or any other thing. It depresses you....You need lots of guidance and support." Participants said they first had to go through the process of grieving the loss of their health, and then periods of denial, anxiety, anger and depression before they were ready to begin to learn about diabetes and self-care. Pam describes her experience.

I had a poor-me attitude for a while there....I felt maybe I could wish it away....That didn't work....I had to do something....I had it and had to accept it....I just had to understand it....After the shock wore off, then I looked at it as just another thing in life to overcome.

She found the more she learned about diabetes the more in charge she was of her health. The time to adjust to the news of diagnosis varied for each participant. They said concern about further health deterioration motivated them to become informed about diabetes. Participants said they came to realize acceptance of a diabetes diagnosis precedes a person's ability to restore harmony in their life.

*Loss of traditional lifestyle.* Taking control of their diabetes also involved participants making a connection to their health and illness beliefs, particularly the traditional Aboriginal role of food. Participants looked to their history. They reflected upon traditional Aboriginal ways of life, events of childhood, and changes imposed on Aboriginal culture that influenced their health. Pam explains that when Aboriginal people led a traditional way of life they ate healthier and were more active. Our old people, you know they never had diabetes or something like that. It just wasn't there because of the way they ate...the diet...activities...and even the walking, walk for miles....People were in pretty good physical shape.

Participants perceived a strong connection to the traditional way of life and good

health. Scott recalled life "spent living in the bush." He said "where I grew up our

family survived by eating healthy." Scott said his family never experienced illnesses

like diabetes until they were acculturated within Euro-Canadian society. Similarly

Pam attributed the decline of Aboriginal people's health with a change from

traditional Aboriginal lifestyle.

We don't take the time anymore....We are so dependent on the modern way of living. This is why these sicknesses catch hold real fast....We used to walk to town, fifteen miles, to get groceries and then we would carry them home....We don't even walk to the store anymore. We drive to the store even if it's just down at the corner.

The components of lifestyle needed to stay healthy are perceived to be lost with

progression from traditional ways of life to the approach of modern society.

Pam and Scott believed that their residential school experiences are in part

responsible for their having diabetes. Pam described the relationship between

residential school, lifestyle change, and health.

In residential school...the food was very scarce. There was a lot of food there, but we weren't given the opportunity to eat that food. So we ate all we got. The kids that went to residential school, they would always sit down and eat all their food.

Pam said the dietary habits of her youth carried over to her life as an adult;

overeating encouraged by fear of going hungry. "We are sitting ducks....All of a

sudden you have all this food and you just start gorging yourself...I think that has a part in the sickness." Participants talked about how Aboriginal people, including themselves, learned to rely on the conveniences of modern society and were taught this was a superior way to live. Ken explained the diet change his family experienced moving to urban society.

I don't believe it is the lifestyle, I think it is the different changes in diet...we aren't used to the refined foods....A lot of urban natives don't have access to the wild foods....My ancestors...lived off the land; they didn't have the sugars or the sweet stuff or anything like that.

Ken felt it is wrong to say that persons' lifestyles are not healthy; to Ken this statement is interpreted as Aboriginal people are choosing to do harm to themselves. What needs to be conveyed are that convenience foods, sedentary lifestyle, and indulgencies of modern society are unhealthy choices. Scott said, "Too much of a good thing is hard for First People's bodies." Participants made connections between the changes in food preferences and the role of food in Aboriginal community life with changes in health. Further, no longer having to physically work for their food, and never before having to create activity specifically for the purpose of exercise, participants perceived that Aboriginal people's health began to deteriorate following adoption of the sedentary lifestyle of modern society.

# Experience of Health Care and Diabetes Education

Participants said they received little information about caring for their health when they were informed of their diabetes diagnosis. They described the advice received from their doctors as "general information" to diet, exercise, and watch their weight. All participants said that their doctors "did not explain diabetes too well" at diagnosis, just told them they "had diabetes." A doctor's prescription for hypoglycaemic medication was the familiar treatment. Participants were either provided a referral to attend diabetes education at a later date, or the diabetes education referral was not received at all. Those diagnosed in the 1970s said they did not receive diabetes education referrals until five or more years later. According to Marie the diabetes education clinic was not operational at that time. Participants said the diabetes education clinic was where they learned about their illness.

Participants spoke about the suitability of health services for Aboriginal people with diabetes. Participants said services were not relevant to their life circumstances and their individual needs. They found health professionals' encouragement of patient autonomy to be limited.

*Relations with health care providers.* Participants, in general, perceived that health care providers did not reinforce the need to follow a diabetes care regimen in order to maintain long term quality of health. The result was participants did not "get serious" about their diabetes right away. Ken describes his perception of the meeting where his doctor told him he was diabetic.

He led me to believe that it wasn't a big deal because it wasn't severe and my numbers weren't that high....He didn't play a part of stressing the fact of how dangerous it can be....It wasn't a problem it seemed....I wasn't severe enough to have to start on pills or insulin, or anything like that.

Ken said it was because of his doctor's relaxed approach that he "didn't really deal

with it." Participants said their doctors' attitudes towards diabetes set the precedent for how they should behave. Marie explained it was difficult for her to make lifestyle changes without the reassurance and understanding of others. "Nobody cared. I should have cared but, I didn't care. My doctor...wasn't supportive at all." Participants lacked motivation to begin self-care at news of their diagnosis.

Participants said they disliked being told by health care providers "what to do" and "what not to do." This made them feel unworthy of participating in treatment decisions. They found diabetes care recommendations to be complicated and unmanageable. Scott describes his reaction to the diabetes care plan he was prescribed. "They set up a very rigid schedule of maintaining your blood sugar level, your medication, adjusting your food intake, your exercise....There is to be excessive change." Scott was overwhelmed by his care plan and said that "having to take two pills...three times a day" distracted him from paying attention to his diet. Participants said problems establishing effective communication with health care providers made it difficult "to ask simple questions" about their self-care plans. Pam explains how interactions with authoritative health care providers are detrimental to self-care.

Disrespect. It always comes back to that. When I don't get respect...I may not listen....The ones that are the most helpful, really care....The ones who I feel respect by as a person not just because I have a condition.

Pam said it is easy to be discouraged from following self-care recommendations when health care providers do not listen to the patient's perspective and individualize the care plan appropriately.

Since their diagnosis a few participants consulted health professionals who routinely provided support and guidance that assisted them in managing diabetes care. These participants reported better control of their health. Ken explains how a new doctor introduced change to his self-care behavior using an approach that gave Ken the confidence he needed to take responsibility for his health. "My doctor is very encouraging and spends a lot of time with me each visit. That was what really got me on track....A motivator. And so I started exercising again and watching my weight." Ken felt valued and cared for by this doctor, "where the patient is someone." His new doctor asked him about his diabetes each time he visited, rather than just treating Ken's presented complaint. Ken suggested that his doctor's encouragement was what enabled him to take responsibility for his diabetes selfcare.

*Accessibility*. A primary concern of participants was the accessibility of health services for Aboriginal people with diabetes. Participants said that there "isn't much out there" in the community where they could receive help with their diabetes. They also felt they were restricted in where they could go for help. Ann said, "There is lots of people out there that don't go nowhere. The people I know with diabetes, they got nowhere to go. Like older people, like me." Participants explained that older Aboriginal people tend not to seek help with their diabetes because they do not realize such services exist; "they don't know there is help." Karen's concern that

people with diabetes are unaware of the community resources available to assist them in their self-care indicates that health care providers may not be informing and encouraging clientele to access such opportunities.

Those participants who sought community resources found the process to be discouraging. Scott shared his experience of trying to find diabetes resources and a program where he would feel welcome. "Everywhere I go it is not being posted or offered....A person has to search and find the information....There needs to be a place to visit, get information, and talk." Scott found that services for people with diabetes were fragmented throughout the city. He and other participants suggested that all persons with diabetes should receive clear notice of community diabetes program opportunities. Ken, active in the health community, felt that he was not always "up to speed with what is going on." A community outreach nurse confirmed that there is poor communication of scheduled diabetes events among health agencies and professionals. All participants said advertisement of diabetes programs and events requires better visibility.

Some participants had difficulty coordinating health appointments with their personal schedules or arranging transportation. Responsibilities of work and family interfered with some participants' abilities to attend daytime appointments; they requested evening and weekend health care and diabetes education opportunities. Participants cited lack of transportation to be a common reason why Aboriginal people can not access health services. Beth said the determining factor of her decisions to attend diabetes education or health appointments is whether she has transportation.

I have to ask somebody to drive me, because I can't walk any more....They had a meeting here for diabetes, but I don't go because there was no way to get there. I wasn't going to get a taxi to go; it's too much for me....If I really have to go to the doctor's office I get a taxi.

Beth's mobility is restricted by her illness. She is restricted on a limited income from spending money on transportation except in emergencies. Participants said delivery of health care and diabetes education services from a central location and providing transportation to persons with limited means or mobility for getting to these services would improve accessibility for Aboriginal peoples.

*Feeling welcome*. Participants felt out of place attending diabetes education programs in acute care facilities. They said such a location was not relaxed: the noise of medical announcements loom in the background. Pam said, "A hospital is too big. There are too many things happening." Participants described the hospitals as "sterile" and "smelly," making them uncomfortable attending programs there. Participants said they felt intimidated among the health care professionals and unsuitably placed with acute care patients in hospital settings.

Pam felt out of place as the only Aboriginal person in a group diabetes education program. "I was the only Native person there....It was very difficult for me." She encountered only one other Aboriginal person at the diabetes education program. Pam said that she felt she did not belong, and the situation interfered with her learning. She suggested that offering a clinic for a group of Aboriginal people in a community setting may facilitate attendance.

So you feel like you are part of something and you are not excluded in any way because of how you look and things like that....When you have a warm gathering in a circle, and see smiling brown faces, I think people feel more comfortable.

Participants felt that a familiar environment and equality among peers would make learning possible. Ann said, "It would be nice for our people to be able to go into a place and they all got diabetes, and they are talking about it"; indicating that other participants have similar wants.

When participants were not individually invited to a diabetes program they assumed they were not welcome or that health professionals did not think it was necessary they attend. Beth said, "They never ask me to go anymore, so I just don't go. If they would ask me I would go. The last one I went to was four years ago." She enjoyed attending the information sessions but did not want to overstep boundaries of politeness and ask to be there. Other participants said they stopped attending diabetes education when they no longer received referrals from their doctor or a call back from the diabetes educators.

Some participants believed that because a program was so busy, there was limited room for persons who had attended in the past. They found appointments with doctors and diabetes educators restricted by tight scheduling. Ann described this rush in her experience first learning to administer her insulin.

To teach me how to give myself a needle...I did it on an orange and then I did it on my body and I hurt myself. It wasn't enough time, because there is me and then they are seeing somebody else....Not even an hour; about 35 minutes....I learned it all on my own since then.

Ann understood that the nurse at the diabetes clinic had a busy schedule, but felt she required more instruction. Participants said they felt rushed by health professionals to learn skills and were not given the time they required to establish comfort and confidence.

Other participants perceived that when they and other Aboriginal people were not referred to a diabetes program or welcomed back, it was because the health professionals were biased against Aboriginal people. Pam said Aboriginal people perceived health workers to be insensitive to the needs of Aboriginal people, "they don't have time to spend with all their clients... it comes across this way." Marie indicated health care workers are quick to assume that Aboriginal people do not want to attend the programs for persons with diabetes. "I keep my appointments. That is very important. You have to keep your appointments, otherwise they look at your record and say, 'She or he doesn't care.'" With limited resources and long waiting lists, Marie said persons who are unreliable and miss their appointments may not receive a referral again. The implication is that health professionals stop inviting Aboriginal people rather than investigate why Aboriginal people are not attending.

*Health literacy.* Participants expressed difficulty in the interviews finding the words to talk about health concerns. When participants were asked, "What is diabetes?" they said they did not know, and described their symptoms or their self-

care plan. Beth said, "There isn't much I could say, because I don't really know." Comments like this indicate a lack of language to describe their experiences and explain their concerns. They considered conversation with health care providers to be intimidating; "There is sometimes I can't understand. It's too complicated, the words, I don't know what they are talking about." Participants said the language used to present diabetes information was sometimes too difficult for Aboriginal people to understand. Karen said this problem becomes worse as a person ages and has difficulty hearing. Participants said the majority of diabetes information was received in written form; people with difficulty reading found this information to be unhelpful. Pam explains that health literacy barriers can deter Aboriginal people from attending diabetes education opportunities.

A lot of our people...don't speak English very good... or can't read or write....They should have an interpreter there to help these people so that they can have their concerns heard....That is why the old people, they don't go.

Participants labeled situations like the one just described as "threatening" and

"complicated," and the learning environment uncomfortable.

Participants asserted that community awareness will improve with delivery of

diabetes education by methods meaningful to Aboriginal people.

Keep it down to simple understanding, because our people have a hard time understanding it. If they don't understand they are not going to say anything....They are just going to let it go....If [health workers] don't take the time to explain to someone who has difficulty learning...the person will feel the health worker is in a rush or on a time limit....Aboriginal people will say they understand when really they don't. Pam said the language used should be simple to help people understand, but, more importantly, health care professionals needed to invest the time and be patient finding ways to help people comprehend the message.

Learning practical self-care skills. Participants found the information about diabetes overwhelming and they often were unable to apply the information they received in their self-care routines. Scott said "It is not just understanding all the concepts of being diabetic...the big question is how." Participants were able to reiterate facts about diabetes, but lacked practical self-care skills. Ken described what he learned about diabetes at a diabetes education program. "Sugar levels are too high in your blood and your pancreas can not develop enough insulin for it....If you don't treat your diabetes and keep your blood sugars at a proper level...other problems could arise." Ken found that information like this did empower him with an interest to take care of his diabetes, but does not provide him with skills to improve his self-care routine. Pam shared her experience after being advised to purchase a blood glucose meter.

When I first got my machine, I was reading it and I didn't know how to operate it. So I didn't use it. It just sat there for a long time. One day I started thinking that I better use this thing but, I had to get educated first.

Pam said she could not get an accurate reading but did not feel comfortable going back to her doctor or a diabetes educator to ask for help. Participants said people who have difficulty understanding written instructions and technology need to be shown how to use their blood glucose meter, as well as how to calibrate it and perform general maintenance. Pam could not be assured of obtaining true readings without such instructions; she was discouraged and did not monitor her blood sugars.

Successful learning methods. Participants said that they needed to learn some amount of new information each time they attended a diabetes education program in order to pique their interest, while a repeat of basic diabetes care was necessary to fine tune and make corrections to their self-care plans. They said programs became tiring when the same information was repeated by the same instructors in different settings. Participants preferred it when the diabetes educators addressed issues specifically relevant to the class and used practical demonstrations to convey their message. They requested "hands-on" and "visual learning" opportunities to learn self-care activities. Karen described the content of a movie she saw at the Aboriginal health clinic. "The movie shows you how to cook. Boiling things mostly, not fry foods, and how there is quite a few different ways....They even show you how to look after your feet." Karen understood the things she needed to do for herself after watching the short video. Instead of the nurse telling her what to eat Karen learned from observing skills in the video; it showed her how to get the task done. Karen was then able to apply the demonstrated life skills into her self-care plan. Participants who have a proficient understanding of English said illustrative teaching was appropriate for all audiences. Ken said he found the simplified "low literacy format" a faster way to learn. "It is very informative and leaves an impression not

easily forgotten." Participants expressed partiality for demonstration and practice activities to deliver disease-specific and diabetes care information.

One way participants have been able to make sense of diabetes and find ways in which to better care for their health is to talk with others who have diabetes. Pam said,

If somebody comes to me that knows they have diabetes then I try to do the best to help as a friend. I try to show them my own respect for diabetes....I talk about and I share my sickness and look towards better ways to healing myself.

Pam went on to say, "Somebody who has been through it them self really understands what they are talking about." Participants said sharing has helped them achieve greater understanding of their illness which enables them better control. Scott explained the advantage of learning this way is that "other diabetics especially people that have adjusted both mentally and physically to being a diabetic" can provide information health educators may not emphasize.

Participants easily associated with "role models" and acquired support from other people with diabetes because "they know what it is like." Karen went five years before learning through a friend that help was available from a nurse at the Aboriginal Health Clinic, and, by referral, to the diabetes education clinic at the hospital. She trusted the advice of her friend. "When I see her she always asks how my diabetes is doing and stuff. If I don't feel good she says, 'try this,' and 'do this,' stuff like that. She has been a diabetic for many years." Karen said there are mental benefits in addition to physical benefits of sharing with other diabetics. It gives you courage and stuff like that. 'Cause well I know I am not the only diabetic. There is quite a few people who is diabetic, and they are going through the same thing I do....Before I felt sorry for myself, and then they started talking to me and I know I am not alone....It give me lots of support.

Participants said they found sharing their experiences of diabetes with other people had the social health benefit of enlisting those people's support and understanding.

*Follow-up*. Participants said that after receiving therapeutic guidelines from their doctor or learning new information at a diabetes education program they were left to their own devices to adapt and maintain their self-care routine. Beth explains she failed to keep to her diabetes care plan. "At the start I really tried to follow what they told me to do, but after a while I just didn't care anymore. I ate whatever I want, and even gaining weight which I am not supposed to." There was no opportunity to go home, practice, and get feedback on her progress. Participants said they did not receive the necessary guidance, continued adjustments and readjustments to see through the recommendations. Pam said, "There needs to be follow-up....They can't expect for the people to go about the recommendations on their own." Participants said they were unaware of opportunities in the health or community settings to get basic assistance with their diabetes self-care plans and support during difficult times.

Participants said during initial diabetes education, the two or three day orientations to diabetes provided by diabetes educators, the educators "go over everything" so the clients could "digest the information." Some participants were asked back approximately a year later to a one-day workshop. The problem for participants was that between these opportunities they progressively forgot information and became discouraged. They found that subsequent appointments followed a standard format with information similar to what was received the first year. For example, participants taking insulin require annual recertification confirming their ability to administer the medication and use a blood glucose meter. Frustration occurs having to repeat something participants know when the time could be better spent learning something the person does not know. Participants suggested that what would have been more helpful was for educators to ask participants what they would like reviewed, allow opportunity for questions to be asked of the educators, and then teach some new up-to-date information and skills.

Participants were invited to make appointments for one-to-one consultation with a dietitian or nurse as needed. Ann tried to access the diabetes nurse for a second appointment to discuss her concerns.

You have to have an appointment because they are so busy. Sometimes you can't see them for at least two weeks. I phone the nurse at the diabetes clinic if I have a problem, but you can never reach her. It is always the answering machine, and they don't return your call until the next day.

What Ann needed was to talk to someone she trusted, knew to be resourceful about diabetes, and who could provide a solution to Ann's concern and calm her fears until she could see one of the diabetes educators or her doctor. Ann's and others' statements in the transcripts indicated that participants were unaware of resources

such as dial-a-dietitian, dial-a-nurse, and their local public health unit to help with answering urgent day-to-day problems concerning their diabetes and other health matters.

Cultural appropriateness. When participants talked about the appropriateness of diabetes services for Aboriginal people they identified concerns with regards to being provided a supportive learning environment and the content being relevant to and respectful of Aboriginal people. Participants said health care workers needed to take note of ways to "honor and respect" individuals using the health service and avoid speaking down to Aboriginal people. Pam said not all health workers were problematic, "they are just trying to do their jobs," but instances happen. Health professionals "have to have a certain rapport, and accept people for who they are....Make sure they are comfortable, and heard." Participants said health professionals tended to discredit the lay perspective of Aboriginal people. Referring to the reaction of a person with diabetes, Scott said, "They will think, 'You don't know what it is like." Problems arose when health care professionals did not see value in the Aboriginal culture and the pride in the "hard life" of the older Aboriginal people. Participants commented on the importance of professionals respecting Elders for their social and educational roles in Aboriginal society. Scott said, "First Nations people don't like being told by younger people that they have to change." Pam said the older people "are so used to being independent," and that in educational settings it is important for this to be accepted.

Life experience, as a part of our culture we look to elders to be our educators and to share their experiences....It is nothing against the young nurse, but they haven't that experience....When the old people have to give that up, that is where some of the difficulty is.

Pam said when the older people are no longer respected for their contribution they feel worthless and devalued. She explained Aboriginal people's health concepts need to be appreciated for being "based on generations of knowledge" and different from the health concepts of professionals which are learned through academic training.

Participants advocated that health professionals needed to "be sensitive in how teachings are worded" in order to make Aboriginal people confident and interested to learn. Scott said, "Present information in a way Aboriginal people can understand without insulting their integrity." All too familiar to Ken was the memory of diabetes education poster campaign that "show a Native sitting on a couch, with a big fat beer belly and a bottle sitting in his hand watching T.V.," with the caption he recalls, "You are probably going to get diabetes." Ken said that just annoyed people and turned them off the campaign. People did not pay attention and the message never got through. Pam cautioned about making assumptions about people, "they generalize that Aboriginal people are all the same." Pam said health care professionals on more than one occasion treated her like "an addict" because she is Aboriginal. She said the health professionals' assumptions annoyed her; had they bothered to ask they would have learned that Pam does not consume alcohol or use recreational drugs.

*Cultural considerations.* Participants indicated that holistic health practices and traditional ways of learning would benefit diabetes programs for some Aboriginal people. They felt Aboriginal people would be better able to identify with diabetes awareness and education programs with these methods. Participants point out that "[cultural protocol] varies with tribes"; indicating diversities of Aboriginal cultures must be considered for health programs to be culturally suitable. Adapting diabetes programs to traditional Aboriginal health practices would not be suitable to every Aboriginal person. Pam and Scott acknowledge that some Aboriginal people would be more comfortable with Euro-Canadian health practices. Pam best described the holistic approach.

The holistic way...you look at everything. How diabetes affects us emotionally, mentally, physically, spiritually, psychologically, and even intellectually....It affects us in all areas. It doesn't just affect our body. It affects every part of our being and our vision. It affects our whole life.

Pam went on to say the holistic approach to her diabetes care "makes it a lot easier." She learned such skills from Elders, Healers, and attending workshops. The traditional Aboriginal method offered motivation and goal-oriented solutions to the emotional experiences that participants said were often not addressed by the diabetes resources and health care services in the community.

Participants said Aboriginal people would traditionally learn about health issues from their peers at the community level. The Aboriginal community works together to look after itself, and this, Scott said, is why "everyone has to participate...mostly it is just sharing the knowledge." Talking about diabetes is an important aspect of the holistic approach. Pam said, "Our people are talkers, mostly oral history, and are taught mostly oral. That is our background, our culture." When people talk about challenges and successes with diabetes they provide to one another advice, recommendations, and guidance. Ken explains which people would traditionally be teaching about diabetes. "Native elders should be involved, and native people who have diabetes should be able to address some of the information as well." Participants said the Native approach goes beyond an informative process. Emotional and spiritual needs are enveloped as well. "It is open with a Native prayer…standing in a circle and holding hands to give [them] spiritual strength." Participants said "Native prayer," opportunities to share with one another, "the talking circle," and learning from all generations are aspects of traditional healing that would be helpful. They reiterated that it is important such discussions be allowed to take place without the limitations of appointments and time restrictions.

Pam and Ann both said they incorporated traditional medicine in their own diabetes self-care plan. The traditional healing practices participants spoke about included praying about their sickness, participating in healing ceremonies, diets that incorporate traditional foods, chewing on roots, and brewing teas from medicinal plants to help keep their bodies cleansed. Pam explained how Aboriginal people historically shared responsibility for the health and well-being of community members and the care of the aged and ill. Traditional healers were consulted for spiritual, mental/emotional, and intellectual advice as well as for physical concerns. Offerings were made out of respect and to acknowledge the healer's gift, but payment for the service was not required. Pam found that in her experience doctors were skeptical of traditional healers and discredited holistic care practices. A community outreach nurse confirmed that this attitude of discrediting traditional healers continues among many health professionals. Aboriginal people are afraid to tell a medical doctor about using traditional remedies because "they don't want to stop the traditional healing...the spiritual." Pam said Aboriginal people have "a history of being ridiculed about their use of herbs and spirituality" in the care of their health, and felt that health professionals "did not value one's perception of their state of health." Half of the participants said they would like to see health professionals accept traditional Aboriginal medicine and approaches to healing as complementary to mainstream health care and have it incorporated into teaching about diabetes self-care.

Participants wanted the problems of lack of available and suitable diabetes awareness and resources for the Aboriginal community to be corrected. Participants took the opportunity during this research to express their concerns and their wishes for betterment for the Aboriginal community. Karen said she saw a benefit to herself and other Aboriginal people with diabetes in her opportunity to tell her diabetes experience to a student. "Students like you...it is very important that you learn...and it is really helpful...like what you are doing, that is how you would be helpful to older people, like what you are doing with me, just talking to them." When asked if

he had any comments or questions about the interview process Scott said, "All these interviews...that you check with First Nations people, that is good." Participants said they felt it is important Aboriginal people with diabetes be asked which services and supports helped them and what issues need improved upon. This research provided them with such an opportunity.

# Challenges to Self-Care

Diabetes affects the physical, emotional, social, financial, and spiritual aspects of the person. Most of the assistance participants received from health care providers was for episodic and acute health concerns. They felt a lack of support for the complex, repetitive and not easily resolved social-health aspects of their diabetes self-care. Participants said diabetes presents a challenge to overcome and incorporate into their lifestyle. They said they needed assistance to gain an advantage over obstacles in way of their self-care success: managing lifestyle modifications, overcoming barriers adhering to treatment regiments, and managing the conflicting demands of everyday life.

Few participants had clear understanding of the relationship that exists between diabetes, medication management without diet and exercise, associated health problems, and mortality. Many loosely followed the recommended diabetes diet and exercise because they had been prescribed hypoglycaemic medication or insulin. Scott said he initially just wanted a quick fix, "just get on the medication," a solution he thought would require minimal effort. Beth did not bother with the knowledge she learned through diabetes education programs "because [she] figured the pills [she] was taking would help." All but one participant used a blood glucose meter to receive feedback in their day-to-day diabetes self-care. However only three participants said they monitored and charted blood sugar levels, and modified insulin, eating and exercise in combination to establish a fine-tuned routine. The others thought pharmaceutical management of diabetes less tedious than the complexities of diet, exercise and medication balance. In contrast, Ken explains that being prescribed medication is a reminder he could improve self-care of his diabetes.

It is more severe because I have to be on pills....If you are not given the prescription to medication, a person has a tendency to think, "Oh, it is not that bad."...What happens is you don't feel sick or feel any different, so why do you have to do all this stuff. Without medication, it doesn't seem real.

Ken alludes to the silent nature of diabetes; when blood glucose levels are stable there are no symptoms and the medications associated with illness are not required. Pam and Karen agreed with Ken, saying that they perceive a prescription to medication as a reminder to focus more efforts on the diet and exercise components of their diabetes self-care.

Many participants had chronic diseases secondary to diabetes such as cardiac and renal conditions. This made it more challenging for them to follow diet and exercise recommendations. Karen's story provides an example. She used to walk a lot to help control her blood glucose levels; now she no longer has the endurance. The most helpful thing for me is to watch what I eat and take my medication on time....I used to do the exercise, I used to walk. Now I can't even walk across the street....Since I had open heart surgery I get tired so easily.

Like Karen, the little walking that Beth could once do now causes her too much pain. "Since those veins that they took off of my legs I can't walk a block....My legs hurt so bad. Before it never bothered me, not until I had this surgery." Other participants with multiple chronic conditions had similar concerns related to their secondary ailments. All participants faced tests of willpower sticking to a diet plan, difficulty achieving daily exercise, and restrictions of a structured lifestyle.

*Personal reactions*. Mood swings and periodic depression were hard for participants to avoid. Participants experienced feelings of deprivation, and fear of indefinite and invasive medication.

Participants said they encountered bouts of depression. Marie said she experienced more difficulty with mood swings and depression in the first few years following diagnosis than she does today. "When you are a diabetic you can be pretty miserable to be around....You have spells...get upset all the time for no reason...anger and depression." Her spells were reactions to high and low blood sugar levels. Keeping diabetes under better control minimizes suffering in this way. Ann talks about feeling despair. "Sometimes I feel so down...sitting there feeling sorry...just waiting to die." These low times Ann experienced were associated with episodes of poor blood sugar control, intensifying symptoms, and health complications. Participants struggled with motivation, time management, and the frustration of having to structure their life plans around meal times and exercise schedules. Beth, Laura, and Ann each said they frequently cheat on their diets and do not exclude the foods they like, particularly high sugar treats. Ken said his troubles occur when he is under emotional stress, "Sometimes I will do it out of spite; I am not allowed to have it so I am going to have it." Karen said she dislikes the repetitive flavour of her diet. "It gets tiresome, what I eat, and I have to be careful all the time. I get discouraged." The restrictions of diabetes therapy elicited feelings of deprivation, and in reaction to these emotions participants at times overate or ate foods not recommended. This repetitive challenge to diabetes self-care resulted in the participants avoiding diet changes and exercise schedules, delaying their ability to take control of their diabetes.

Associating insulin with increasing severity of illness and fear of needles diverted participants from recommended therapy. Beth, Marie, Laura, and Ann all said they at first were "scared to death" of the thought of self-administering needles. Laura's story depicts the trauma experienced when informed she required insulin to control her diabetes.

I ran away from my needle for about six months. I didn't even know what I was going to do. I hate needles to start with....I didn't take my needle for a week and I went into a diabetic coma.

Laura said she learned from her experience never to miss a dose of insulin. She laughed during this part of her interview and said, "Now [the needle] is nothing, just

nothing to me now."

*Social circumstances.* Diabetes and its emotional challenges affected participants' social interactions. Ken said the difficulty is in part because a person with diabetes can never escape their illness. "It is like a little person sitting on your shoulder and nagging at you all the time." Participants said that because of the changes to their lifestyles they experienced difficulty and discomfort interacting socially at home or with friends. Ken said family members could not understand the emotional and physical difficulties the person diagnosed with diabetes was experiencing.

If the family doesn't understand they can't support the person with diabetes. I am often criticized because I am not dealing with diabetes, but they don't know what it is like....The criticism is more hurtful than good, but they think they are helping me.

Ken's family unintentionally placed an extra burden upon him, creating an uncomfortable situation in his self-care management. Socializing and preserving healthy personal relationships were especially hard for participants. Marie spoke of her experiences. "If I got to go out to supper with my family....They would invite me over and I would have to wait an hour...two hours. I can't do that, I have to eat." Participants could no longer eat and drink the same foods as family and had to strictly follow meal schedules. They had greater difficulty socializing publicly and with friends. Marie did not change her social behavior at first; "Everybody is eating and drinking; I went a few times and it wasn't good for me." Participants felt out of place and perceived themselves to be difficult guests. Ken said "it is my perception, I feel different"; he knows his friends do not intentionally treat him differently. He said they "don't understand the struggles that the person with diabetes is going through," and do not know what to say or how to act around the person with diabetes.

Participants either said managing diabetes conflicted with their employability or that being employed made it difficult to find the time for self-care. Participants' work environments contributed to physical and emotional stress, adversely affecting their health. Many lost their ability to work because of diabetes. Shift work was particularly problematic because of the difficulties establishing a routine. The experience of Ann provides an example; she explained why she could no longer work. "The job is shift work, and I don't get to eat right. I get so tired and I don't eat for hours. That's what drove my sugar right up." The conditions of Ann's employment did not allow her to schedule small meals throughout her workday. She was unable to keep her blood glucose under control. After long work days, participants said they did not "have the energy; not only physically but mentally as well," for diabetes self-care. Work stress and time management difficulties compounded already poor health and reduced blood sugar control.

*Expense of self-care*. As discussed in Chapter 2, good health is costly; a decrease in health problems is observed with increasing income. Persons with low income and no financial security have increased stress in life and decreased time and energy for preventative health behaviour. Financial barriers are one reason

Aboriginal persons may not adhere to treatment recommendations. All participants commented on the costs of self-care: diabetic food, medication, and exercise.

Participants emphasized that the expense incurred with diabetes competed with the costs of basic needs including food, shelter, and clothing. For some participants, diets recommended for diabetes management required participants to purchase foods beyond their means. Laura was both frustrated and insulted when told she should attend a shopping tour class.

A meeting for diabetics and heart disease where somebody takes us around in the grocery store and tells us what to buy. I didn't go for that because I know what I can buy. I know what I can eat and what I can't eat. It is costly to buy those things. It is a waste of time and money to me.

Laura was accustomed to a limited selection of foods she was used to cooking and knew she could afford. She was afraid to experiment with new foods on her minimal income. Laura could not afford to waste food or she would not have enough to eat. She said it would be helpful for the dietician to watch what she buys and then make healthy recommendations still within her budget.

Participants' reactions to paying for exercise were similar. They could not afford extras including user fees and gym memberships. Beth said, "I am not spending money on exercise...I wouldn't have no money for it." Exercise opportunities were associated with user fees or costs of appropriate attire, a great expense during winter months. Transportation to exercise locations and costs associated with access to community leisure services exceeded participants' budgets. Two participants did not have "status" designation and did not receive medical benefits to assist with the cost of medication and health care supplies required for diabetes self-care. Ann could not afford her rent and household expenses let alone exorbitantly priced medication.

I only get \$376 every two weeks....I am having problems paying my bills....I gotta buy pills again and bottles of insulin....All my needles and stuff. It is all so expensive....I need these pills bad. Ninety-eight dollars I paid for them last time. I can't afford to get them.

Her income was less than her bills. She was very ill with an infection. Ann opted not to take her insulin as she could not afford to pay for it. Her blood sugars became extremely elevated and her body unable to heal. Suffering in pain, Anne did not have energy or willpower and found it extremely difficult to solve her own health crisis. Participants in financial need were not always aware of services or were intimidated by forms required to get assistance with health care expenditures.

Summary

Participants' experiences living with diabetes ranged from the frightening shock of diagnosis to the daily challenges of maintaining control of their diabetes, and their experiences of health services. They emphasized the need for greater diabetes awareness and availability of suitable resources for the Aboriginal community. Most significant was the call for self-management support. Identified were ongoing issues of cultural desideratum that need to be overcome by way of considering Aboriginal culture, history, and socio-economics. In the following discussion, the potential for doing so in consideration both of these data and published literature is explored.

#### **Chapter 5: Discussion and Conclusions**

The objective of this study was to explore urban Aboriginal peoples' perspectives on diabetes and their experiences using health services. The input of urban Aboriginal people was sought because of that population's high risk for diabetes, low utilization of existing resources, and above average rate of diabetesrelated morbidities. One of the findings was that participants' patterns of health services utilization, both in coming to diagnosis and in support of their diabetes selfcare, related to their prior experiences with health services and their socioeconomic circumstances. Further, lack of resources and information appropriate to participants' needs created difficulties in their making lifestyle changes for diabetes management.

This study is one of only a few (Gregory et al., 1999; Hagey, 1984; Travers, 1997) designed to gain an understanding of urban Canadian Aboriginal people's perceptions about diabetes and their health care experiences. Qualitative methodology allowed the participants to express, in their own words, their experiences, feelings and thoughts. This process brings participants' voices into the results. However, this technique has limitations.

Notably, in qualitative studies, the researcher's personal experience and interests affect the interpretation of the results. To counteract this, I took note of my own expectations and assumptions before and during the interviews. Findings that emerged from the first interviews were validated with participants during the second interviews. Furthermore, as the interviews took place over five years before the writing of the final report, services may have changed. This does not seem to be the case, however. Confirmation that the study findings remain current was verified in the year prior to writing by one participant who works in the health care sector and by a community outreach nurse from the study community.

It was anticipated that with English being a second language for most participants there may be some limitation on the information received. This seemed to have occurred in two ways. Firstly, there was a lack of depth in some of the participants' responses. Secondly, participants' use of silence during the interview or lack of answer to a question may not have to do with their lack of opinion regarding the interview question but have more to do with language or with respect for health care professionals and a desire not to criticize them.

Generalizations cannot be made from the study due to the small number of participants and the tenets of qualitative methodology which attends to meaning in experience rather than representiveness. The themes addressed are limited to the scope of the research questions. It was not the intention of this researcher to measure the success of Aboriginal liaison and employee cultural sensitivity programs of the health region, or to evaluate diabetes education resources. The results however provide insight into issues underlying the success of urban Aboriginal people's selfcare of diabetes and what health services are needed to assist them in self-care.

## Navigating Health Resources

In general, participants of the study felt powerless when navigating health services and as a result, they became accustomed to problems created by having diabetes. The majority of participants did not seek services of a doctor at first signs of health change because they were not socialized to bring their early concerns to the attention of a doctor in an effort to prevent greater health problems. They had difficulties using the Canadian health care system; what experiences they did have were not always pleasant. Participants' health beliefs were mainly comprised of information handed down from extended family. Consistent with Shestowsky (1995), participants' sources of information about health and related services were most often informal networks. Participants also said that they made limited use of diabetes resources including education clinics and community organizations, a finding consistent with prior studies examining urban Aboriginal people's experience of health services (Gregory et al., 1999; Shestowsky).

The results indicated that participants' lack of confidence when going to the doctor may relate to prior experiences of not being taken seriously; some instances were described as humiliating and discriminatory. Generally people will make fewer health care visits when they do not feel accepted as a result of discrimination, and thus leave symptoms untreated until they become unbearable (Rambo, 1984). Literature supports the finding that Aboriginal peoples' lack of familiarity in using health services relates to a history of encountering degrading experiences including

restricted access to services. Browne and Fiske (2001) found similar results in a reserve community in northwest Canada. As the result of years of sociopolitical pressures to be unassertive when dealing with issues of personal health, as well as perceiving their health concerns were not taken seriously by health care providers, Aboriginal women "may wait until their condition was severe before seeking services" (p. 134). Browne and Fiske link the "paradoxical situations" of Aboriginal people's health encounters to the history of Aboriginal peoples in northwestern Canada; specifically residential school exploitations, colonial legacy in health and social service sectors, lack of regard for Aboriginal people's socioeconomic circumstances, and negative stereotyping. Participants stated in the present study that they continue to encounter discriminatory attitudes on part of some health care providers to this day, consistent with other research exploring urban Aboriginal people's.

Few participants went for health check-ups prior to their diagnosis with diabetes. This tendency to not make preventive doctor visits is exacerbated by a shortage of doctors; such is the case in Northern British Columbia. Episodic health care does not encourage the development of a rapport between client and doctor, and reduces opportunities for diabetes screening. In such situations it is more difficult for the doctor to diagnose chronic illness and harder for the client to accept news of a diagnosis. Further, the first access to the health system does not need to be a doctor. Diabetes screening could be provided by a nurse.
Participants were shocked when told they had diabetes; some had not realized they were at risk for diabetes prior to diagnosis. As in other research, among both Aboriginal (Gregory et al., 1999) and non-Aboriginal (Adriaanse et al., 2002) people with diabetes, participants who had family members with diabetes were more likely to have some knowledge about diabetes before diagnosis. All participants had prediagnosis symptoms of diabetes in contrast with the findings by Sunday and Eyles (2001) whose participants had not experienced classic symptoms. Participants in the present study said awareness among the urban Aboriginal community of diabetes risk factors, symptoms associated with illness, and the value of early diagnosis continue to be limited.

Some information sources about diabetes and lifestyle choices unintentionally give the message that the patient is to blame for his/her illness (Garro, 1995). Participants made associations between shame, personal fault for diabetes, and the perception that diabetes care is the individual's responsibility. Such perceptions appear to deter members of the urban Aboriginal community from openly discussing diabetes. Though some participants indicated they shared their diabetes experiences with others, they all said diabetes was not commonly talked about in the community, inhibiting both the dissemination of diabetes awareness and support for persons with diabetes. Participants found it difficult to maintain health routines without support. Diabetes patient-education often occurred in isolation from family and community, and few participants had family and friends take an interest in healthy lifestyle

changes. Similar to other Aboriginal people with diabetes, as reported in research by Boston et al. (1997), Sunday and Eyles (2001), and Grams et al. (1996), participants in the present study expressed frustration that family, friends, and members of the community critique their diabetes care practices.

Participants found the usual methods for delivering health information unsuitable for urban Aboriginal people with language and literacy limitations. Health care providers' reliance on lectures about abstract concepts to convey diabetes information restricts some participants' learning what they must do to care for their health. Language and literacy difficulties interfere with understanding health terminology as well as application of the teachings (Dufton, 1992; Shestowsky, 1995). Written materials in particular were perceived to be problematic both for diabetes awareness and for providing information on self-care to diabetic clients. People who have difficulty reading avoid newspapers, booklets, and pamphlets; they lack confidence in their own comprehension and are made uncomfortable by unfamiliar health concepts and terminology. Written health messages, as a result, often go unheard. Gregory et al. (1999) and Farkas (1984) similarly found the provision of pamphlets on diabetes to urban Aboriginal clients problematic because of literacy problems and the fact that reading was not the preferred method to learn. The results of the present study indicated that when information was not easily learned or applied to daily life, participants were less likely to return to the program or follow recommendations for diabetes management.

For many participants, the lifestyle changes required by diabetes were perceived as drastic and overwhelming, and beset by problems related to participants' socioeconomic circumstances. Most affected by income was participants' access to health services. Those with jobs experienced difficulty taking time from work, and in some instances lost wages, which interfered with their ability to coordinate health appointments. In cases where participants received social assistance, some chose not to attend health appointments and diabetes education programs because they could not afford transportation, or perceived they would not be able to afford to put into practice what they expected to learn. Costs of foods required for diabetic diet and diabetic supplies, not to mention costs of transportation and exercise, competed with the person's other expenses. Travers' (1997) research on urban Aboriginal peoples' experiences of diabetes also revealed that costs of recommended foods were of concern to persons on social assistance. Bell (1991) found the basic support allowance of the government of British Columbia's social assistance program was insufficient to cover the minimum cost of a nutritionally adequate diet. Bell found that after paying for food, there was no money left over for the purchase of household supplies, or personal care and clothing expenses, which are also meant to be covered by the basic support allowance.

### Interactions with Health Care Providers

Participants' responses to diagnosis and initiation of self-care were, in part, reflections of their interactions with health care providers. For example, the ways in which participants were informed by their doctors of the seriousness of diabetes and the strategies to tighten metabolic control and reduce incidence of complications affected participants' understanding of how to live a healthier longer life. Further, when health professionals did not ask the participant for input into decisions about their diabetes care, the expectations were perceived as unrealistic. Participants' frustration over failing health led to poor satisfaction with their health care providers and increased life stress, which in turn further decreased their self-confidence and success managing diabetes.

Participants found that when doctors explained the prognosis of diabetes they understated the seriousness of the illness. Consistent with the study by Travers (1997) the findings of the present study showed terminology such as "borderline diabetes" and suggestions that elevated glucose levels are not a serious problem allowed participants to dismiss the importance of lifestyle changes. In the present study participants said their doctors did not explain well the preventative role of diet and exercise; prescriptions of medications to manage symptoms of diabetes were perceived to be the common treatment. This finding perhaps indicates that doctors either expected information on lifestyle change would be received by participants through the diabetes education clinic or assumed that Aboriginal clients would not follow lifestyle change recommendations. As in other studies (Daniel et al., 1999; Travers), some participants were not referred by their doctor to diabetes education. "Being denied access to diabetes education meant being denied the opportunity to prevent the progression of diabetes and to enhance well-being" (Travers, p. 8). Some participants were not informed that additional support was available through other health resources. The health services most participants received appear to fall short of the clinical practice recommendations for continuing diabetes education and follow-up doctor visits to take place every two to four months (Harris, Meltzer, & Zinman, 1998; Young et al., 2000).

Most participants stated that they did not make requests for services to meet their needs when not satisfied with the care received. For example, few would ask to go to the diabetes education clinic for an update. Some participants lacked knowledge of the help that is available to assist them in managing diabetes. When information about care options is misunderstood they may be too embarrassed to ask for clarification. The tendency of mainstream health practitioners is to interpret the Aboriginal person's reluctance to speak of health needs as resistant and nonassertive behavior (Browne & Fiske, 2001). In contrast, researchers and participants suggest that Aboriginal people's non-confrontational approach is the product of socialization; they fear that challenging the health professional's authority will be perceived impolite and offensive (Browne & Fiske; Sunday & Eyles, 2001). Further, when a few participants approached health or social assistance providers about their financial concerns and health they encountered resistance. This finding relates to the common misunderstanding on the behalf of service providers, including health professionals, that all Aboriginal people receive free medical care, medications, and related expenses (Browne & Fiske; Maidman, 1981; RCAP, 1996).

Difficulty communicating their problems and concerns to health professionals left participants feeling intimidated. This trend has been found in a number of other studies. Participants perceived health professionals to be judgmental of participants' circumstances, and felt that they were not given opportunities to discuss concerns about their health and have a say in self-care. Other researchers exploring the experiences of Aboriginal people labeled similar experiences "feeling dismissed" (Browne & Fiske, 2001, p. 133), and "rushed" (Gregory et al., 1999, p. 109). Shestowsky (1995) found urban Aboriginal people perceived health care providers to be "distant, uninterested in the Aboriginal client" (p. 24). As in other studies (Cosby & Houlden, 1995; Gregory et al.; Hagey & Buller, 1983), participants in the present study perceived the diabetes care guidelines received from health care providers to be "rule-bound" (Gregory et al., p. 109) causing participants to feel as if they were being told what to do and what not to do. This finding is not unique to Aboriginal people. Callaghan and Williams' (1994) study of people's perceptions of living with diabetes in England found that if patients believed they were not considered individually by their care providers they would "simply go away and do what they think is best for them[selves]" (p. 136). When people feel alienated and

lack confidence, they often will just agree with the health care provider so as not to disappoint or feel different or embarrassed (Rambo, 1984).

Participants did not find health care providers took time to verify what the participants understood. The health care provider's agenda often did not match the participants' perceived needs. As in other studies (Cosby & Houlden, 1995; Gregory et al., 1999; Garro, 1995) when participants did not understand the rationale behind their health care provider's recommendation for diabetes care they either chose to ignore what the health care provider told them, or stopped making an effort to change their lifestyle when, after trying to follow the recommendations, they saw no improvement to their health. These problems may result in avoidance of required health services (Callaghan & Williams, 1994; Shestowsky, 1995), and are made worse by lack of follow-up with the same care provider (Cosby & Houlden). Avoidance and not following diabetes care recommendations are often interpreted by health care providers as poor compliance. When health care providers are perceived as critical by clients, they are less likely to work as a team. Health professionals need to shift their approach "from what should be done to what the individual feels might help" (Dufton, 1992, p. 123).

In contrast, a few participants experienced relationships with health professionals that involved shared decision making; increased involvement in decision making increased participants' satisfaction with their provider, success with diabetes care, and positive health outcomes. When health care providers

108

acknowledge the parts of a participant's lifestyle that are positive, this conveys to the participant that they are making progress. By allowing the participant to identify improvements to their diabetes care that they feel comfortable and confident making, change becomes acceptable. Those participants who said they made decisions with their doctor or a diabetes educator about their health care were more successful in their disease management. As described by Browne and Fiske (2001) and Gregory et al. (1999), participants were motivated by health professionals who conveyed respect for participants' decisions by taking the time to further elaborate on diabetes information, answer questions, and provide emotional support.

# **Implications**

The findings revealed the need for greater efforts towards community-based education and health care services aimed at 1) reduction of diabetes risk, 2) screening, 3) early diagnosis, 4) symptoms management, and 5) prevention of disease progress. Based on the results, implications for programs and services as well as health care providers are presented.

*Implications for programs and services*. As discussed in Chapter 2, a fundamental problem of the current health system is that services are not adequate to meet the health resource needs of people with chronic disease. This problem was found to be true for the participants of this study. Recent advances towards health care systems change through application of the chronic disease prevention and management model appear to be positive steps that may offer solutions to the unmet

needs of urban Aboriginal people with diabetes. The study findings indicate participants would benefit from self-management skills development through partnership between patient and health care provider, with support of selfmanagement education groups.

Participants desire community-based health resources in coordination with culturally appropriate learning practices. The findings of this study support other reports (BCPHO, 2002; Bobet, 1998) which recommend that campaigns target the Aboriginal community to increase awareness of Aboriginal people's risk for chronic illnesses and promote healthy food choices and physically active lifestyles as means of prevention. Increased community-wide awareness of diabetes and healthy lifestyles has been seen in other community-based intervention research (Daniel & Gamble, 1995; Heffernan et al., 1999) and may be an outcome of community-based self-management education opportunities. Thus far studies of chronic disease selfmanagement programs have focused on outcomes for participants (McGowan, 2002; McGowan, 2004).

Self-management education groups offer participant-directed content and delivery (IHI, 2002b) and thus can be structured according to urban Aboriginal people's expressed needs, including the degree to which cultural attributes are incorporated. As in other urban Aboriginal studies (Gregory et al., 1999; Travers, 1997), participants in the present study desired to try traditional foods and traditional healing approaches in diabetes management. Standard diabetes education materials

110

are designed for middle-class Caucasian clientele and adaptations, for Aboriginal clients include simplified language and cultural symbolism at best. Such minimal alterations of the materials do not make them culturally suitable. One concern is that to treat all Aboriginal peoples as one does not acknowledge their cultures' diversities, which is demeaning (Farkas, 1984; RCAP, 1996). Further, the study findings indicate that teaching methods and materials need to be frequently evaluated and revised according to Aboriginal clients' learning needs and health literacy levels. The Institute of Healthcare Improvement (2002b) recommends that health care professionals "have focus groups from the community help select teaching tools appropriate for the population" (p. 60).

Participants typically found health care providers taught too much information at one time. "Diabetes education programs often offer intensive education over the course of a few days. While efficient for the educators, this format may not be best for learning and the development of self-care behaviors" (Dufton, 1992, p.124). Additionally, participants expressed too much emphasis was placed on the physiology and symptoms of diabetes, with little or no mention of the underlying causes. Other studies concur that clarifying the etiology of diabetes might help understanding how to manage diabetes (Garro, 1995; Gittelsohn et al., 1996; Grams et al., 1996). More frequent diabetes education sessions (Dufton), such as with the patient-directed self-management education format (IHI, 2002b; McGowan, 2002; McGowan, 2004) facilitate better patient self-care. Opportunities for selfmanagement education should continue throughout the client's lifetime.

Participants desired opportunities to learn about diabetes, develop selfmanagement skills and receive support, and wanted education sessions to be open to family, friends, and community. These desires can be addressed within selfmanagement education groups. As in other studies (Fuller, 1991; Gregory et al., 1999; Hagey, 1984; Shestowsky, 1995; Travers, 1997), participants in the present study requested healing circles and teachings by and for Aboriginal people with diabetes. These activities encourage the discussion of personal experiences with diabetes, provide opportunities to learn ways of coping, and relieve feelings of isolation and uncertainty. Recently a self-management education program surfaced in the study community; seven participants from the Nechako-Fraser Junction Métis Elder Society were enrolled in the summer of 2003. This initiative is ongoing (McGowan, 2002) and, based on the experiences of other Aboriginal communities (Diabetes Healing Trail, 2004), will likely prove successful.

Lastly, the study findings indicate multidisciplinary collaboration is important to meet the holistic needs of urban Aboriginal people. Participants said that professionals of allied health services should share client information and together customize resources to clients' needs. The chronic disease management model promotes use of systems for patient management and communications between a patient's health care providers. Further, health services in support of diabetes

112

management need to be integrated with resources respectful of Aboriginal people's socioeconomic circumstances and cultural values. One way to achieve this goal is to deliver interdisciplinary services through community-based primary health care clinics (RCAP, 1996; Shestowsky, 1995; Wagner et al., 2001). In the past year the Central Interior Native Health Society in Prince George has taken such an approach to delivery of client services. The health care system is in transition and approaches to services to Aboriginal people with diabetes may have improved in some areas. Nevertheless, the issues presented in this thesis remain important.

*Implications for health care providers*. Some general implications for health care professionals emerge from this study. The findings emphasize the importance of health care providers' participation in chronic disease management initiatives and related professional development opportunities to learn how to help patients achieve self-management. First, similar to other reports (RCAP, 1996), the findings of the present study indicate the need of Aboriginal people to be recognized as experts in their own health and health care. Second, to problem solve their self-care routines participants are in need of convenient access to health care professionals for advice and support. Third, discrepancies between clinical practice guidelines for diabetes care, including screening and diagnosis, and the average level of health care most participants of this present study received could be improved upon if health care providers adopted chronic disease management tools and resources. Fourth, health professionals need to become more knowledgeable about and supportive of clients'

use of community resources.

The findings also revealed that health care providers could improve their knowledge of local Aboriginal people's cultures and traditions, socioeconomic circumstances, and health issues and challenges. Other reports suggest this may help promote sensitivity and responsiveness to Aboriginal people and their needs (AHABC, 1999; RCAP, 1996). This is an important area of study for students of the health care professions; however, in-service education, preferably delivered by members of the local Aboriginal community, is necessary to keep health care providers up to date.

## Implications for Further Research

At the same time health services in Canada are undergoing restructuring to better meet the demands of clients with chronic illness, restrictions on government spending requires redistribution of health care funds to maintain current programs. The results of this study suggest that diabetes-related health resource needs of urban Aboriginal people in Prince George are not being met by existing health services. Further research should include a larger scale needs assessment. Evaluation projects of interventions such as community-based self-management education programs may provide opportunities for collection of qualitative and quantitative data while supporting the Aboriginal community in addressing a gap in health resources.

## Conclusions

This study explores some key issues relevant to urban Aboriginal people's experiences with diabetes and with health services. The findings confirm that Aboriginal people encounter difficulties accessing health services as result of social, cultural, and economic circumstances. Further reinforced is the need for changes to the health care system that will result in improvements to health status for people with diabetes. The findings indicate that participants would attend diabetes education programs and services more often if they were of better quality, patient centered, and culturally relevant. There is need for health services to be driven by clients' perspectives and expressed needs rather than the disease process. The study points towards the important role of family and community in health and wellness initiatives. Another implication of the study is for community-based holistic approaches to health care that involve integration of multidisciplinary programs and services. It is hoped that the findings might inform the process of program improve aimed at providing Aboriginal people opportunities to be better informed about diabetes and empowered to increase their participation in decisions concerning their health.

#### References

- Aboriginal Health Association of British Columbia. (1999). *Health authorities handbook on Aboriginal health*. Unpublished report. (Available from the BC Aboriginal Network on Disability Society, 1179 Kosapsum Crescent, Victoria, BC, V9A 7K7).
- Adriaanse, M. C., Snoek, F. J., Dekker, J. M., van der Ploeg, H. M., & Heine, R. J. (2002). Screening for type 2 diabetes: An exploration of subjects' perceptions regarding diagnosis and procedure. *Diabetic Medicine*, 19, 406-411.
- Anderson, R. M. (1985). Is the problem of noncompliance all in our heads? *The Diabetes Educator, Spring*, 31-34.
- Bauman, L. J. & Greenberg Adair, E. (1992). The use of ethnographic interviewing to inform questionnaire construction. *Health Education Quarterly*, 19, 9-23.
- Barr, V. J., Robinson, S., Marin-Link, B., Underhill, L., Dotts, A., Ravensdale, D., et al. (2003). The expanded chronic care model: An integration of concepts and strategies from population health promotion and the chronic care model. *Hospital Quarterly*, 7, 73-82.
- B. C. First Nations Regional Health Survey. (2000). *Our Nations on the edge of a new century*. Retrieved June 6, 2004, from <a href="http://www.fnchc.ca/publications.html">http://www.fnchc.ca/publications.html</a>
- Bell, P. (1991). Economic barriers to optimum nutrition in Native communities in British Columbia. *Arctic Medical Research, Suppl.*, 756-757.
- Bobet, E. (1998). *Diabetes among First Nations people*. Ottawa: Health Canada. Cat. no. H34-88/1998E.
- Bodenheimer, T., Lorig, K., Holman, H., & Grumbach, K. (2002). Patient selfmanagement of chronic disease in primary care. *Journal of the American Medical Association, 288*, 2469-2475.
- Booth, G. L. & Hux, J. E. (2003). Relationship between avoidable hospitalizations for diabetes mellitus and income level. *Archives of Internal Medicine*, *163*, 101-106.

- Boston, P., Jordan, S., MacNamara, E., Kozolanka, K., Bobbish-Rondeau, E., Iserhoff, H., et al. (1997). Using participatory action research to understand the meanings Aboriginal Canadians attribute to the rising incidence of diabetes [Electronic version]. *Chronic Diseases in Canada*, 18(1), 1-12.
- British Columbia. (1995). *Report of the northern and rural health task force*. Victoria, British Columbia: Ministry of Health and Ministry Responsible for Seniors.
- British Columbia. (2003a). Chronic disease prevention & management. BC Health Services update, September 2003. One year in review. Retrieved May 26, 2004, from http://www.healthservices.gov.bc.ca/cdm/research/update2003.pdf
- British Columbia. (2003b). Chronic disease management. Building the vision in British Columbia. BC chronic disease management update, March 2003. Retrieved May 26, 2004, from http://www.healthservices.gov.bc.ca/cdm/research/updatemar03.pdf
- British Columbia. (2004a). *Chronic disease management in BC*. Retrieved May 26, 2004, from <u>http://www.healthservices.gov.bc.ca/cdm/cdminbc/index.html</u>
- British Columbia. (2004b). *Managing your chronic illness: Information for patients. The chronic disease self-management program.* Retrieved May 26, 2004, from http://www.healthservices.gov.bc.ca/cdm/patients/managing.html
- British Columbia. (2004c). *Guidelines & Protocols Advisory Committee. Diabetes Care. Revised 2004.* Retrieved May 26, 2004, from <u>http://www.healthservices.gov.bc.ca/msp/protoguides/gps/diabetescare/diabetes</u> <u>care.pdf</u>
- British Columbia Provincial Health Officer. (2002). Report on the health of British Columbians. Provincial health officer's annual report 2001. The health and well-being of Aboriginal people in British Columbia. Victoria, British Columbia: Ministry of Health Planning.
- British Columbia Vital Statistics. (2002). Regional analysis of health statistics for Indians in British Columbia: 1991-2001. Birth Related and Mortality Summaries for British Columbia and 16 Health Service Delivery Areas. British Columbia Vital Statistics Agency, Ministry of Health Planning, Province of British Columbia and First Nations and Inuit Health Branch, Health Canada.

- Browne, A. J. & Fiske, J. A. (2001). First Nations women's encounters with mainstream health care services. Western Journal of Nursing Research, 23, 126-147.
- Bruce, S. (2000a). Prevalence and determinants of diabetes mellitus among the Métis of western Canada. *American Journal of Human Biology*, 12, 542-551.
- Bruce, S. G. (2000b). The impact of diabetes mellitus among the Métis of western Canada. *Ethnicity & Health*, 5(10), 47-57.
- Bryant, J. (1999). Preventive cancer screening: Social determinants of participating in mammography and pap tests. Unpublished master's thesis. Prince George, British Columbia: University of Northern British Columbia.
- Burnard, P. (1994). Searching for meaning: A method of analyzing interview transcripts with a personal computer. *Nurse Education Today*, 14, 111-117.
- Callaghan, D. & Williams, A. (1994). Living with diabetes: Issues for nursing practice. *Journal of Advanced Nursing*, 20, 132-139.
- Canadian Diabetes Association. (1997). *About diabetes*. Retrieved November, 1997, from <u>http://www.diabetes.ca/aboutdia/general.html</u>
- Canadian Diabetes Association. (2000a). *Diabetes in British Columbia*. Unpublished report. (Available from the Canadian Diabetes Association, Suite 360 1385 West 8<sup>th</sup> Avenue, Vancouver, BC, V6H 3V9).
- Canadian Diabetes Association. (2000b). *Diabetes in the Northern Interior Health Region*. Unpublished report. (Available from the Canadian Diabetes Association, Suite 360 1385 West 8<sup>th</sup> Avenue, Vancouver, BC, V6H 3V9).
- Canadian Diabetes Association. (2003a). *The prevalence and costs of diabetes*. Retrieved December 15, 2003, from http://www.diabetes.ca/Section\_About/prevalence.asp
- Canadian Diabetes Association. (2003b). Heart disease epidemic looms. *Diabetes Dialogue, Spring*, 30.
- Canadian Diabetes Association. (2003c). Organization and delivery of care. Canadian Diabetes Association Clinical Practice Guidelines Expert Committee. Clinical Practice Guidelines for the Prevention and Management of Diabetes in Canada. *Can J Diabetes*, 27(Suppl. 2), S14-S16.

- Cosby, J. L. & Houlden, R. L. (1995). Health beliefs towards diabetes mellitus in two Ontario First Nations populations. *Canadian Journal of Diabetes Care*, 20(2), 12-19.
- Daniel, M. & Gamble, D. (1995). Diabetes and Canada's Aboriginal peoples: The need for primary prevention. *International Journal of Nursing Studies*, 32, 243-259.
- Daniel, M., Green, L. W., Marion, S. A., Gamble, D., Herbert, C. P., Hertzman, C., et al. (1999). Effectiveness of community-directed diabetes prevention and control in a rural Aboriginal population in British Columbia, Canada. Social Science & Medicine, 48, 815-832.
- Davis, C. (2002). Chronic disease management model. In Health Association of BC (Ed.), Strategic workshop on chronic disease management proceedings, March 27, 2002 (pp. 4-8). Retrieved May 26, 2004, from http://www.healthservices.gov.bc.ca/cdm/research/proceedings.pdf
- Diabetes Healing Trail: Urban Aboriginal and Métis Diabetes Prevention & Control. (2004). Retrieved June 7, 2004, from http://www.diabeteshealingtrail.ca/about.html

Dufton, B. (1992). Barriers to diabetes self-care. Beta Release, 16, 119-125.

- Farkas, C. (1984). Nutrition education planning for Native Canadians: An application of the ethnography of communication. Unpublished doctoral dissertation. Toronto, Ontario: University of Toronto.
- Fox, C., Harris, S. B., & Whalen-Brough, E. (1994). Diabetes among Native Canadians in Northwestern Ontario: 10 years later. *Chronic Disease in Canada*, 15(3), 92-96.
- Fuller, C. A. (1991). Diabetic diet management: A Native Indian perspective. Unpublished master's thesis. Vancouver, British Columbia: University of British Columbia.
- Gamble, D. (1993, February). Development and evaluation of an Aboriginal community directed NIDDM primary and secondary prevention programme (NHRDP file no. 6610-2016-49ND). Funding application submitted to the National Health Research and Development Program, Department of National Health and Welfare Canada. Unpublished document, Okanagan University College, Kelowna, British Columbia, Canada.

- Garro, L. C. (1995). Individual or societal responsibilities? Explanations of diabetes in an Anishinaabe (Ojibway) community. *Social Sciences & Medicine*, 40, 37-46.
- Gittelsohn, J., Harris, S., Burris, K., Kakegamic, L., Landman, L. T., Sharma, A., et al. (1996). Use of ethnographic methods for applied research on diabetes among Ojibwa-Cree Indians in Northern Ontario. *Health Education Quarterly*, 23, 365-382.
- Glasgow, R. E. & Anderson, R. M. (1999) In diabetes care, moving from compliance to adherence is not enough [Letter to the editor]. *Diabetes Care, 22*, 2090-2092.
- Grams, G.D., Herbert, C., Heffernan, C., Calam, B., Wilson, M. A., Grzybowski, S., et al. (1996). Haida perspectives on living with non-insulin-dependent diabetes. *Canadian Medical Association Journal*, 155, 1563-1568.
- Gregory, D., Whalley, W., Olson, J., Bain, M., Harper, G. G., Roberts, L., et al. (1999). Exploring the experience of type 2 diabetes in urban aboriginal people. *Canadian Journal of Nursing Research*, 31, 101-115.
- Guba, E. G. & Lincoln, Y. S. (1981). *Effective evaluation*. San Francisco, CA: Jossey-Bass Publications.
- Hagey, R. (1984). The phenomenon, the explanation and the responses: Metaphors surrounding diabetes in urban Canadian Indians. *Social Science & Medicine*, 18, 265-272.
- Hagey, R. & Buller, E. (1983). Drumming and dancing: A new rhythm in nursing care. *The Canadian Nurse*, 79(4), 28-31.
- Harris, S. B., Gittelsohn, J., Hanley, A., Barnie, A., Wolever, T. M. S., Gao, J., et al. (1997). The prevalence of NIDDM and associated risk factors in Native Canadians. *Diabetes Care*, 20, 185-187.
- Harris, S. B., Meltzer, S. J., & Zinman, B. (On behalf of the Steering Committee for the Revision of the Clinical Practice Guidelines for the Management of Diabetes in Canada). (1998). New guidelines for the management of diabetes: A physician's guide. *Canadian Medical Association Journal*, 159, 973-978.

- Health Association of BC. (2002). *Strategic workshop on chronic disease management proceedings, March 27, 2002.* Retrieved May 26, 2004, from http://www.healthservices.gov.bc.ca/cdm/research/proceedings.pdf
- Health Canada. (2000). *Diabetes among Aboriginal people in Canada: The evidence*. Ottawa: Health Canada. Cat. no. H35-4/6-2001E.
- Health Canada. (2002). *Diabetes in Canada* (2nd ed.). Ottawa: Center for Chronic Disease Prevention and Control. Population and Public Health Branch. Health Canada.
- Health Canada. (2003). A statistical profile on the health of First Nations in Canada. Retrieved June 6, 2004, from <u>http://www.hc-sc.gc.ca/fnihb-dgspni/fnihb/sppa/hia/publications/statistical\_profile.pdf</u>
- Heffernan, C., Herbert, C., Grams, G. D., Grzybowski, S., Wilson, M. A., Calam, B., et al. (1999). The Haida Gwaii diabetes project: Planned response activity outcomes. *Health and Social Care in the Community*, 7, 379-386.
- Herbert, C. P. (1996). Community based research as a tool for empowerment: The Haida Gwaii diabetes project example. *Canadian Journal of Public Health*, 87, 109-112.
- Hjelm, K., Mufunda, E., Nambozi, G., & Kemp, J. (2003). Preparing nurses to face the pandemic of diabetes mellitus: A literature review. *Journal of Advanced Nursing*, 41, 424-434.
- Holsti, O. R. (1969). *Content analysis for the social sciences and humanities*. Reading, MA: Addison-Wesley Publishing Company.
- Institute for Healthcare Improvement. (2002a). *Health disparities collaboratives*. *Changing practice changing lives. Training manual.* Retrieved June 2, 2004, from http://www.ihi.org/collaboratives/
- Institute for Healthcare Improvement. (2002b). *Health disparities collaboratives*. *Changing practice changing lives. Diabetes.* Retrieved June 2, 2004, from <a href="http://www.ihi.org/collaboratives/">http://www.ihi.org/collaboratives/</a>
- Jacobs, P., Blanchard, J. F., James, R. C., & Depew, N. (2000). Excess costs of diabetes in the Aboriginal population of Manitoba, Canada. *Canadian Journal* of Public Health, 91, 298-301.

- James, R., Young, T. K., Mustard, C. A., & Blanchard, J. (1997). The health of Canadians with diabetes. *Health Reports*, 9(3), 47-52.
- Jin, A., Martin, J. D., & Sarin, C. (2002). Diabetes mellitus in the First Nations population of British Columbia, Canada. Part 2. Hospital morbidity [Abstract]. *International Journal of Circumpolar Health*, 61, 254-259.
- Johnson, S., Martin, D., & Sarin, C. (2002). Diabetes mellitus in the First Nations poplutation of British Colubia, Canada. Part 3. Prevalence of diagnosed cases. *International Journal of Circumpolar Health*, 61, 260-264.
- Krippendorff, K. (1980). Content analysis: An introduction to its methodology. London: Sage.
- Kwan, K. (2003, July 23). Man dies in police custody. Prince George Citizen, p. A1.
- Lofland, J. & Lofland, L. H. (1995). Analyzing social settings. A guide to qualitative observation and analysis (3rd ed.). Belmont, CA: Wadsworth Publishing Company.
- Lorig, K. (2003). Self-management education. More than a nice extra. *Medical Care*, *41*, 699-701.
- Lorig, K. R. & Holman, H. R. (2003). Self-management education: History, definition, outcomes, and mechanisms. *Annals of Behavioral Medicine*, 26, 1-7.
- Lorig, K. R., Ritter, P., Stewart, A. L., Sobel, D. S., Brown, B. W., Bandura, A., et al. (2001). Chronic disease self-management program: Two-year health status and health care utilization outcomes. *Medical Care*, *39*, 1217-1223.
- MacDonald, F., Shah, W. M., & Campbell, N. M. (1990). Developing the strength to fight diabetes: Assessing the education needs of Native Indians with diabetes mellitus. *Beta Release*, 14, 13-16.
- Macgregor, A., Ravensdale, D., & Barr, V. (2002). Chronic disease model the BC collaborative experience. In Health Association of BC (Ed.), *Strategic workshop on chronic disease management proceedings, March 27, 2002* (pp. 11-14). Retrieved May 26, 2004, from http://www.healthservices.gov.bc.ca/cdm/research/proceedings.pdf

- Maidman, F. (1981). Native people in urban settings. Problems, needs, and services. A report of the Ontario task force on Native people in the urban setting. Unpublished manuscript.
- Marin-Link, B. (2002). The BC strategy for diabetes prevention and management. In Health Association of BC (Ed.), *Strategic workshop on chronic disease management proceedings, March 27, 2002* (p. 16). Retrieved May 26, 2004, from http://www.healthservices.gov.bc.ca/cdm/research/proceedings.pdf
- Martin, D. (1995). A statistical report on the health of First Nations in British Columbia. Vancouver, British Columbia: Medical Services Branch, Health Canada.
- Martin, J. D. & Yidegiligne, H. M. (1998). Diabetes mellitus in the First Nations population of British Columbia, Canada [Abstract]. *International Journal of Circumpolar Health*, *57*, 335-339.
- McGowan, P. (2002). Implementation and evaluation of self-management programs in BC and Canada. In Health Association of BC (Ed.), *Strategic workshop on chronic disease management proceedings, March 27, 2002* (pp. 9-10). Retrieved May 26, 2004, from http://www.healthservices.gov.bc.ca/cdm/research/proceedings.pdf
- McGowan, P. (2004). The diabetes self-management program in British Columbia. Project evaluation. Retrieved June 25, 2004, from http://www.healthservices.gov.bc.ca/cdm/research/dsmpevaluation.pdf
- McLeod, B. (1997). Diabetes education: New directions for program development. Oakville, Ontario: Pocket Press.
- Miles, M. B. & Huberman, A. M. (1994). *Qualitative data analysis* (2<sup>nd</sup> ed.). Thousand Oaks, CA: Sage.
- Millar, W. J. & Young, T. K. (2003). Tracking diabetes: Prevalence, incidence and risk factors. *Health Reports*, 14(3), 35-47.
- Morse, J. M. (1994). Designing funded qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 220-235). Thousand Oaks, CA: Sage.
- Morse, J. M. & Field, P. A. (1996). *Nursing research. The application of qualitative approaches* (2nd ed.). New York: Chapman & Hall.

- Northern Health. (2004). Northern Health chronic disease prevention and management strategic plan – draft. Unpublished report. (Available from the Northern Health Manager Health Service Integration, 543 Front Street, Quesnel, BC, V2J 2K7).
- O'Neil, J. D. (1986). The politics of health in the fourth world: A northern Canadian example. *Human Organization*, 45, 119-241.
- Paterson, B. (2001). Myth of empowerment in chronic illness. *Journal of Advanced Nursing*, 34, 574-581.
- Pope, C., Ziebland, S., & Mays, N. (2000). Qualitative research in health care. Analysing qualitative data. *British Medical Journal*, 320, 114-116.
- Rambo, B. J. (1984). Adaptation nursing. Assessment and intervention. Philadelphia, PA: W.B. Saunders Company.
- Redman, B. K. (2004). *Patient self-management of chronic disease: The health care provider's challenge*. Boston: Jones and Bartlett.
- Royal Commission on Aboriginal Peoples. (1993). *Aboriginal peoples in urban centres*. Ottawa: Author.
- Royal Commission on Aboriginal Peoples. (1996). Report of the Royal Commission on Aboriginal Peoples [Electronic version]. Ottawa: Author.
- Schillinger, D., Grumbach, K., Piette, J., Wang, F., Osmond, D., Daher, C., et al. (2002). Association of health literacy with diabetes outcomes. *Journal of the American Medical Association*, 288, 475-482.
- Shah, C. P. & Dubeski, G. (1993). First Nations Peoples in urban settings: Health issues. In R. Masi, L. Mensah, & K. A. McLeod (Eds.), *Health & Cultures. Exploring the relationships: Policies, professional practice and education* (pp. 71-93). Oakville, Ontario: Mosaic Press.
- Shestowsky, B. (1995). Health-related concerns of Canadian Aboriginal people residing in urban areas. *International Nursing Review*, 42, 23-26.
- Spradley, J. P. (1979). *The ethnographic interview*. New York: Holt, Rinehart, and Winston.

- Statistics Canada. (1991). *Reference guide to community profiles: Aboriginal Peoples Survey*. Ottawa, Ontario: Supply and Services Canada.
- Sunday, J. & Eyles, J. (2001). Managing and treating risk and uncertainty for health: A case study of diabetes among First Nation's people in Ontario, Canada. *Social Science & Medicine*, *52*, 635-650.
- Travers, K. (1997, October). The social organization of inequities in health: Cape Breton Mi'Kmaq communities and diabetes. Paper presented at the 4th International Conference on Diabetes and Indigenous Peoples, San Diego, CA.
- Von Korff, M., Glasgow, R. E., & Sharpe, M. (2002). Organising care for chronic illness. *British Medical Journal*, 325(July), 92-94.
- Von Korff, M., Gruman, J., Schaefer, J., Curry, S. J., & Wagner, E. H. (1997). Collaborative management of chronic illness [Electronic version]. Annals of Internal Medicine, 127, 1097-1102.
- Wagner, E. H., Grothaus, L. C., Sandhu, N. S., Galvin, M. S., McGregor, M., Artz, K., et al. (2001). Chronic care clinics for diabetes in primary care. A systemwide randomized trial. *Diabetes Care*, 25, 695-700.
- Waldram, J. B. (1995). Physician utilization and urban Native people in Saskatoon, Canada. Social Science & Medicine, 30, 579-589.
- Waldram, J. B., Herring, D. A., & Young, T. K. (1995). Aboriginal health in Canada. Historical, cultural, and epidemiological perspectives. Toronto, Ontario: University of Toronto Press.
- Wilson, K. & Rosenberg, M. W. (2002). Exploring the determinants of health for First Nations people in Canada: Can existing frameworks accommodate traditional activities? *Social Science & Medicine*, *55*, 2017-2031.
- Wolpert, H. A. & Anderson, B. J. (2001). Management of diabetes: Are doctors framing the benefits from the wrong perspective? *British Medical Journal*, 323, 994-996.
- Woolfson, P., Hood, V., Secker-Walker, R., & Macauley, A. C. (1995). Mohawk English in the medical interview [Abstract]. *Medical Anthropology Quarterly*, 9, 503-509.

- Young, T. K. (1993). Diabetes mellitus among Native Americans in Canada and the United States: An Epidemiological review. *American Journal of Human Biology*, 5, 399-413.
- Young, T. K. (1994). The health of Native Americans. Towards a biocultural epidemiology. New York: Oxford.
- Young, T. K., Reading, J., Elias, B., & O'Neil, J. D. (2000). Type 2 diabetes mellitus in Canada's First Nations: Status of an epidemic in progress. *Canadian Medical Association Journal*, 163, 561-566.
- Young, T. K., Szathmary, E. J. E., Evers, S., & Wheatley, B. (1990). Geographical distribution of diabetes among the Native population of Canada a national survey. *Social Science & Medicine*, 31, 129-139.

Appendix A

Appendix B

•

Appendix C

## **Interview Questions**

- 1) Tell me about the time when you learned you had diabetes?
- 2) How would you describe diabetes?
- 3) How did you learn about diabetes and about how to manage your diabetes?
- 4) If you have received any help for your diabetes from a health care provider
  - a) describe the types of things you found most helpful?
  - b) describe the types of things you found least helpful?
- 5) Describe any difficulties you have with caring for your diabetes?
- 6) What would make it easier for you to manage your diabetes?
- 7) What effect has diabetes had on your family and friends?
- 8) What kinds of programs/ services do you believe are needed in Prince George for Aboriginal people with diabetes?

Appendix D

#### Explanation to Participants of the Study

My name is Gillian Tyson. I am a community health graduate student at the University of Northern British Columbia. I am presently conducting a study in partnership with the Central Interior Native Health Society (CINHS).

The purpose of this study is to gather and record information about the perspectives of urban Aboriginal people on appropriate diabetes health education and support services. This will be done by interviewing urban Aboriginal people with diabetes who live in Prince George. This study will benefit urban Aboriginal people by providing participants who are members of the urban Aboriginal community with an opportunity to express their point of view and expectations regarding this study topic. The information from these interviews will assist health care agencies like the CINHS to make future recommendations and plans for urban Aboriginal diabetes health education and support services.

I would like to invite you to participate in this study. To recruit participants I have asked the CINHS nurse to review this letter with you.

Participating in the study will involve two interviews approximately one and a half hours each. During these interviews I will ask you questions about your diabetes and your experiences with health education and support services. Additionally, I will be asking for your impressions and expectations about diabetes health education and support services which you feel would be appropriate to urban Aboriginal people in Prince George. The interviews will take place at the CINHS at a time convenient for you. With your permission interviews will be audio taped and journal notes will be taken. Transcriptions of what was said in the interviews will be made. Your name will not be associated with the study. Pseudonyms will be used to replace any names, places, or other identifying features that appear on the interview tapes; the tapes will be transcribed and coded to ensure there in no identifying information on the transcripts. During the study the tapes and transcripts will be stored in a secure place by the researcher. The only persons who will listen to the audio tapes or read the transcripts will be the researcher and her supervisory committee from UNBC. Following the successful defence of the researcher's thesis the tapes will be confidentially stored at the CINHS. With your permission these tapes will be used by the CINHS to assist in the possible development of a future diabetes health education and support programme for urban Aboriginal people.

If you agree to do the interviews your participation will be voluntary. You may withdraw at any time without repercussions. You may stop the audio tape at any time as well as refuse to answer questions. Your participation will have no effect upon the treatment or care you receive from the CINHS. You will remain anonymous in the study.

Following the study you will receive a photocopy of the final report. Additionally, a presentation will be made by the researcher to the urban Aboriginal community and the Central Interior Native Health Society in which you will be invited to attend.

If you are interested in participating in this study please inform the CINHS nurse. She will take your name and phone number so that I may contact you to schedule and interview time. If you have any questions or require more information please ask that I call you. You are welcome to keep this letter. Thank you for your time.

## Informed Consent and Agreement to Participate

## A Study of Urban Aboriginal People's Perspectives about Appropriate Diabetes Health Education and Support Services

The aim of this study is to collect information about the views of urban Aboriginal people for suitable diabetes health education and support services. This study will benefit the Aboriginal people in Prince George by giving them the opportunity to share their point of view, expectations, feelings, and experiences about:

a) their diabetes,

b) the diabetes health education and support services, and

c) what diabetes health education and support services they feel would be

helpful to urban Aboriginal people in Prince George.

This study will help health care agencies, like the Central Interior Native Health Society, to make plans for better diabetes health education and support service programs for Aboriginal people in Prince George.

I have agreed to participate in the two interviews for this study. I have been told about the study and what is expected of me. I understand that I will be asked questions about my diabetes and experiences with diabetes health education and support services. I will also be asked about my view and feelings regarding the diabetes health education and support services that I think would be helpful to urban Aboriginal people. I have been told that the interviews will take place at the Central Interior Native Health Society (CINHS) and will last around one and a half hours each. I am aware that the interviews will be audio taped and the university student researcher will take notes.

I am aware that there are no risks or benefits for me in this study. My name will not be used in the study. I understand that during the study the tapes and written information will be stored in a locked cabinet by the researcher, Gillian. The tapes will be destroyed after five years. I understand that my participation is voluntary. I may withdraw at any time without penalty. I also know that I may stop the tape as well as refuse to answer any questions. I have been informed that my participation will have no bad effect on the treatment or care I receive from the CINHS. If I want to have the CINHS nurse with me in the interview I may ask to do so at this time. I understand that no one will be told that I was in the study.

I have read and agree to this letter. I have been given a copy of this letter.

	Date	•
Signature of participant		

Date\_\_\_\_\_

Signature of Researcher (Interviewer)

If you have any questions about the study please feel free to contact the Gillian through the Central Interior Native Health Society or at the UNBC address below. If you should ever have any questions about your rights as a participant in this study, please contact the Dean of Graduate Studies at UNBC (phone number: 960 5555).

Gillian Tyson (Graduate student researcher)
c/o Community Health Programme
University of Northern British Columbia
3333 University Way
Prince George, B. C.
V2N 4Z9

If you would like a summary of the results please print your mailing address on this page.

Name	 	· · · · · · · · · · · · · · · · · · ·	
Mailing			
Address			-

Appendix F
# MEMORANDUM OF AGREEMENT

Research Partnership between the Central Interior Native Health Society and Gillian Tyson, Community Health Graduate Student, University of Northern British Columbia

### Proposed research project

Urban Aboriginal people's perspectives about appropriate diabetes health education and support services.

## Study purpose

Diabetes has been identified as a problem of epidemic proportion for Aboriginal people throughout Canada that is further compounded by a lack of adequate diabetes programmes, services and resources for Aboriginal peoples (Lillie, 1992). In a study of patient perspectives of diabetes care and education Wikbald (1991) reports that educating and supporting people with diabetes to manage their disease in the context of their daily life are among the most important goals to achieving successful diabetes care. With prevalence rates on the rise, the timing for special health education and support services which support urban Aboriginal people in British Columbia to deal with the everyday dilemmas surrounding diabetes is of utmost importance. This is a descriptive qualitative exploratory study of the perspectives of urban Aboriginal people of Prince George about appropriate diabetes health education and support services which will serve as a preliminary step towards developing effective diabetes programmes.

## Research relationship

On June 18, 1997 the Central Interior Native Health Society's Board of Directors endorsed the partnership between the CINHS and the researcher so that the researcher may pursue the above proposed research project for the purpose of the partial completion of the requirements of a M.Sc. in Community Health and in a working relationship with the CINHS staff. It is envisioned that the results of this study will help Aboriginal organizations in Prince George (including the CINHS) to determine if an urban Aboriginal diabetes healing program is warranted, and if so, to identify some of the parameters to be further investigated in the process of program development. Consistent with the strategic plan of the Central Interior Native Health Society, this research will, in addition to being a starting point for the development of new programs which are appropriate to urban Aboriginal people, defend and support proposals to grant agencies for funding, and provide information to help to expand program service to match the needs of urban Aboriginal people who are not currently clients of the CINHS.

### Protection of the interests of the Central Interior Native Health Society and the researcher

The Central Interior Native Health Society and the researcher have identified a number of shared concerns which this document will clarify and confirm:

### 1. Research product

The Central Interior Native Health Society will receive one bound copy and one electronic (computer disc) copy of the research report (researcher's thesis).

### 2. Ownership of data

Following completion of the research project and the successful defence of the researcher's Master's thesis, the CINHS will retain ownership of the primary data collected including interview surveys and audiotapes. Nevertheless, the CINHS will provide access to the research student and other authorized representatives of UNBC to the data to be used for the purpose of replication or reanalysis of data used in the thesis. The data collected during the