

# **LIFESTYLE CHOICES OF PATIENTS WITH TYPE 2 DIABETES**

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A thesis submitted to the Faculty of Graduate Studies  
In Partial Fulfillment of the Requirements for the Degree of  
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**Lifestyle Choices of Patients with Type 2 Diabetes**

**BY**

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**A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University of  
Manitoba in partial fulfillment of the requirement of the degree**

**Of**

**Master of Science**

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## **Abstract**

**BACKGROUND:** Diabetes type 2 is chronic disease that is well researched in the past, but there is not a lot done to explain patient's perspectives on how they manage the disease. This thesis reports the findings of a study to determine the major reasons for lifestyle choices in diabetes 2 patients (Aboriginal and Non-Aboriginal). **OBJECTIVES:** The aim of this thesis is to portray how people with type 2 Diabetes live and what is their perception on relative cost in living with the disease and to compare Aboriginal and Non-Aboriginal population in how they perceive their control of their disease. **DESIGN AND SETTING:** This qualitative study used in-depth interviews and was carried out at HAC Winnipeg. **PARTICIPANTS:** The study population consisted of 38 people with type 2 Diabetes (Aboriginal and Non-Aboriginal). **METHOD:** Data were collected using food choice map and analyzed by using content analysis. **RESULT:** The core themes were found. :” maintenance of weight”, ” maintaining weight and desire for foods”, ”food as a temptation”, ”fear of diabetic complications”, ”depression”, ”fatigue and tiredness”, ”resistant to the diet”, ”trust in health care professionals”, ”family tradition: cooking”, ”just eating normally”, ”unfocused eating and food preferences”, ”ability to buy food”, ”living alone”, ”alcohol and friends”, ”family” and ”social life”. **CONCLUSION:** Complex psychosocial factors influence decision-making process in lifestyle choices of both groups. Further research is needed to investigate which decision-making process patients with type 2 Diabetes employ.

*This thesis is dedicated to my son Bojan*  
*Posveceno mom sinu Bojanu*

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## CHAPTER 1: INTRODUCTION

The reasoning behind the lifestyle choices of patients may never be fully understood. Studies in the growing area of qualitative research literature with people that have diabetes have suggested that by understanding the patient's perspective it will be possible to help them achieve their goals. This may improve disease management and more fully define the role of the patient in type 2 diabetes (Funnell & Anderson 2000; Hjelm et al.,2005).

Type 2 diabetes is a global epidemic and is especially prevalent in the Canadian Aboriginal community (Yung at al, 2000, Harris at al., 1996). It has a multifactorial etiology (genetic, behavioural and environmental factors) which is documented in the literature, though how these factors intertwine is not well understood (Narayan, 2002; Yung et al., 2000). Understanding of the discrepancy between cultures in disease management is also limited (Shimizu & Paterson , 2007,Wise et al, 2001).

Type 2 diabetes is a chronic disease which is hard to treat and hard to manage due to the complexity of the treatment regime and the extended need for self-care that puts a significant amount of pressure on patients. The concerns of the patient and health care provider surrounding the illness and treatment often differ (Funnell, at al., 2000). It is important to understand the patient's perspective on disease management to be able to provide better health care.

The relationship between a health care provider and a patient is very important. It is crucial for the provider to understand which methods a patient has to implement to minimize the impact of their disease on daily living. The necessary trust and

understanding for maximum treatment benefit stems from a mutual understanding between patient and provider. The patient must believe that the provider has his best interests in mind to gain the full benefit of treatment and a provider must understand and be sensitive to the social and economic circumstances of a patient's life.

The main rationale for this study is to gather information and interpret it in a way to help health care workers to better understand patient motivation to adhere to treatment, which could eventually improve the management of clinical disease outcomes. The information could clarify the role of the patient and provide more insight into managing the disease. Managers at the community clinic were interested in the outcome of the study because they felt that would lead to a better understanding of their patients. The expectation was that better understanding would assist the staff in improving services for patients and their day to day management of the disease.

In order to gain a better understanding of the lifestyle choices that patients with type 2 diabetes have to make and to be able to learn more about the secondary issue of the possible differences between Aboriginal and non-Aboriginal patients, this study was conducted in the core area of Winnipeg. It has high rates of type 2 diabetes as well as a high number of Aboriginal patients.

Qualitative interview is chosen is to deeply explore the respondent's point of view, feelings and perspectives. The food choice map was the main tool for data collection. The interactive food choice map helped patients to speak openly about their dietary choices, exercise regimes and others aspects of living with diabetes they found important to them. Utilizing content analysis, the underlying reasons behind behaviour

were found, analyzed and presented in order to reveal a patient's main coping strategies and to better understand the social cost involved in living with the disease.

The information gathered in this study provides us with greater insight on the reasoning behind a patient's choices, coping mechanisms and the cost of living with the disease. It is the researcher's hope that the data contained in this thesis will allow for the implementation of new management and coping techniques designed for and with sensitivity to type 2 diabetes patients.

The main question that this study addresses is: "*What are the perceptions of people with diabetes of the social, economic or psychological costs experienced as a result of living with the condition?*" The study aims to describe perceptions related to control, reasons for lifestyle choices and experience of relative cost of having diabetes. "Relative cost" is defined as emotional, monetary and other costs that are relevant to a patient's perspective of reality. The patient's overall perception on disease control is investigated. Possible differences in the perceptions of Aboriginal and non-Aboriginal patients may also be identified.

## **CHAPTER 2: LITERATURE REVIEW**

This literature review is separated into six themed sections. The first section discusses type 2 diabetes, its prevalence in Manitoba (specifically in the Aboriginal community) and its management. It looks at the complex factors that promote or hinder patient compliance with treatment on the individual level. It is followed by looking specifically at the reasons for lifestyle choices in both Aboriginal and non-Aboriginal cultures.

The second section reviews determinants of patient adherence. This review is complicated by the diversity of the research objectives and methodologies among similar studies, though it attempts to demonstrate what has been done to augment the variety and to identify and explore the gap in our knowledge of patient adherence. This part of literature review shows how health professionals are exposed to a common way of thinking that could add to the stress patients perceive.

The third section focuses on the patient-centered approach and influences on food behaviour in diabetes management. This part of literature review explained the movement from adherence to patients' empowerment. Qualitative research plays an important role in understanding patients' perspectives, which may increase the awareness of health practitioners to help empower their patients.

The fourth section reviews the influence of food behaviour on type 2 diabetes disease management. The review shows the Aboriginal culture context and explores the many complex factors may underlie patient perspectives on how they manage their diabetes.

The fifth section reviews the interview-based studies and their results as well as the complex reasons that people have for their behaviour and how the Aboriginal and non-Aboriginal population experience living with type 2 diabetes. This part of literature review increases an understanding of current knowledge, and finding in knowledge, related to lifestyle choices of type 2 diabetic patients.

The sixth section of the literature review examines the broader context of what lifestyle means and how it is defined and viewed by different healthcare providers, religious and societal groups, and to explore what the societal and political influences on the decision-making process regarding lifestyle choices would be. This part of literature review shows that general societal values may influence different SES groups to have different perceptions on lifestyle and that may be adding further stress to type 2 diabetes patients with lower SES.

## **2.1. Type 2 Diabetes in Manitoba**

Diabetes Mellitus is an endocrine disease resulting from a deficiency of insulin, leading to hyperglycemia and possible long-term complications. Type 2 diabetes can result from insulin resistance in the body's tissues or a secretory deficit in the pancreas. The major health consequences associated with type 2 diabetes are hyperglycemia, hypoglycemia, and ketoacidosis. Long-term complications include macrovascular complications (cardiovascular disease, cerebrovascular disease, and peripheral vascular disease) and microvascular complications (retinopathy, nephropathy, neuropathy and foot problems) (Barnett, & Cumar, 2004).



This study was done in Winnipeg therefore it is important to understand the extent of the type 2 diabetes problem in Manitoba. In Manitoba, type 2 diabetes is quickly becoming an epidemic in First Nations communities. It has also become rampant in the senior population (Manitoba Health, 1998). According to Manitoba Health (1998) more than 55,000 people in Manitoba have been diagnosed with diabetes; 13% of people over 55 years and 15% of people over 65 years have been diagnosed with diabetes; more than 20% of Status Aboriginal women and 13% of Status Aboriginal men over the age of 25 have been diagnosed with type 2 diabetes. These estimates pertain to 1996.

The prevalence of diabetes is now very high among Manitoba's senior population. More than 1% of Manitobans aged 55 and older develop diabetes each year. Generally, two-thirds of persons with diabetes are age 55 and older (Manitoba Health, 1998). These estimates pertain to 1996, and combined with the report on cost on diabetes and its complications for 1995, lead to the establishment of the Diabetes Steering Committee in 1997 to coordinate development of Diabetes Strategy for Manitoba.

### ***2.1.1 Type 2 Diabetes in the Aboriginal Community***

Before 1950, type 2 diabetes was rare in Aboriginal populations (Young et al., 2000). Type 2 diabetes mellitus is now recognized as a major health problem among Aboriginal people. Age-adjusted prevalence rates are 19% to 26% (Delisle & Ekoe, 1993; Harris et al., 1997).

Complications of diabetes become important factor in the experience of First Nations peoples of the disease burden, which greatly affects quality of life (Young et al., 2000). First Nations men and women on reserve have three times the rate of heart

problems and hypertension compared to the general Canadian population (First Nations and Inuit Regional Health Survey National Steering Committee, 1999). The prevalence of hypertension among First Nations adults with type 2 diabetes was 43% compared to 10% of those without diabetes (Bobet, 1997). The prevalence of diabetic nephropathy is 25% to 60% following 15 to 20 years with diabetes (Whiteside, 1994). Among First Nations people living in Manitoba, there has been an increase in dialysis of more than 400% since 1987 (Manitoba Health, 1999). The prevalence of diabetes among Manitoba First Nations people living on a reserve was reported to be 18 times higher than all other Manitobans (Martens et al., 2007).

### ***2.1.2. Type 2 Diabetes Treatments and Management***

Type 2 diabetes is difficult to treat. It is a complex multifactorial disease, involving the interaction of genetic susceptibility and environmental factors. Although many environmental factors associated with type 2 diabetes have been described, their etiological contributions in the development of the disease are not well understood. These factors include obesity, body fat distribution (Chan et al., 1994; Haffner et al., 1990), diet (Colditz et al., 1992; Marshall et al., 1994) and physical inactivity (Erikson, 1996; Hamman, 1993). Many of the factors appear to be related to individual behaviour, cultural environments, and a broader social context.

Treatment of type 2 diabetes often starts with lifestyle treatment strategies including home blood glucose monitoring, exercise, stress control and diet management strategies such as meal planning (Bantle, 1988).

In type 2 diabetes nutritional approaches are oriented towards improving glucose and lipid levels through diet modification and weight loss when appropriate (Brown et al., 1996, Cumming et al.2002, Nutall & Chasuk,1998). A stepwise increase in physical activity may improve glycemic control and reduce the need for medication (Schneider et al., 1992). Self-monitoring is useful for people with type 2 diabetes. It is recognized that weight loss and maintenance in the overweight or obese diabetic is more difficult than in the non-diabetic (Broom et al., 2004). The person with type 2 diabetes is educated in how to use a glucose meter, how to interpret the results, and how to modify treatment according to blood glucose levels. Many people with type 2 diabetes can control glucose levels through a special diet and the use of oral medication. Many others may become refractory to the diet and oral medication and will require insulin for better control.

Type 2 diabetes education for health care professionals and those affected by it plays an important role in the tertiary prevention of the disease. There are insufficient data on how many people with the disease in Canada receive education on self-management. A U.S. National Health Interview survey found that only 35% of people with type 2 diabetes had attended a class or program about it. The UKPDS has shown that tight control of blood sugar and blood pressure reduces the rate of microvascular disease and macrovascular disease (Stratton, et al., 2000).The management of hyperlipidemia also prevents the development of macrovascular disease in people with the disease. For all people with type 2 diabetes, regular foot and eye examinations with proper preventive treatment can prevent amputations (Litzelman at al.,1993), and the development of retinopathy (Murphy,at al., 2004)

Self care is an important part of diabetes management in order to reduce diabetic complications. Diabetes self care management is complex because it does not only include the use of medications but also appropriate knowledge or information, lifestyle behaviors (diet and physical activity), skill to regulate glucose by self-monitoring of blood glucose (SMBG), skills to prevent and identify diabetic complications (e.g. foot care) and coping skills to improve psychosocial function using empowerment techniques or encourage self-efficacy or relaxation (Norris et al., 2001).

## **2.2. Adherence to Treatment (Compliance)**

“What’s the hardest thing about taking care of people with diabetes?”(Funnel & Anderson, 2000). Many health care providers would answer that patients with type 2 diabetes do not do what they are told. It is common to hear them express frustration and sorrow that their patients just don’t follow their diet or exercise plans, that they don’t check their blood sugar or even take their medicine (Funnel & Anderson, 2000)).

The problem of compliance and control in the treatment of diabetes is commonly recognized. Research over the last 25 years has shown that the diabetic patient’s adherence to medical advice is a multi-factored phenomenon. The best adherence can be obtained if the real needs of the patient are met, matching therapy with their representations and expectations and acknowledging the constraints that everyday life puts on the individual. This doesn’t merely include the physical burden of the disease but the social and personal experience of the patient (Gentili et al., 2001)

Researchers have shown better adherence for medication use than for lifestyle change (Anderson & Fitzgerald, 1993). Adherence rates of 65% were reported for diet

(Glasgow et al., 1986) but only 19% for exercise (Kravitz et al., 1993). Two studies demonstrated that adherence to oral medications in patients with type 2 diabetes was 67% when measured by electronic monitoring (Mason et al., 1995; Paes et al., 1997).

“Despite the improved technology, however, patients often do not adhere well to this aspect of the diabetes regimen” (SMBG- self monitoring of blood glucose). A recent study using a large national sample of patients with type 2 diabetes found that 24% of insulin-treated patients, 65% of those on oral medications, and 80% of those treated by diet and exercise alone either never performed SMBG or did so less than once per month. Daily SMBG (at least one blood glucose check per day) was reported by only 39% of patients treated with insulin and by just 5% of those treated with either oral medications or diet and exercise (Delamater, 2006).

SMBG has become a standard of care in the management of diabetes. It is recognized as being important in these situations: sensitizing the type 2 diabetic patient to the advantages of diet control and physical exercise, determining and adapting the dosage of oral antidiabetic medication at the beginning of treatment or during a dosage change, and monitoring plasma glucose during disease or treatment that may lead to blood glucose imbalance (Le Dévéhat, 2006).

Patients have to prepare the lancing device by inserting a fresh lancet and then have to arrange the blood glucose meter and test strips. Next step in the process is to use the lancing device to get a small drop of blood from the fingertip and apply the blood drop to the test strip in the blood glucose meter. The results are present on the meter after several seconds. The recommendations for frequency of testing vary from one person to

another based upon individual factors such as type of treatment (diet versus oral medication versus insulin), level of hemoglobin, and treatment goals (Harris, 2001).

In one qualitative study (Peel et al., 2007) exploration was made about patients' views about self monitoring. Patients tended not to act on their self monitoring results, in part because of a lack of education about the appropriate response to readings. Some participants continued to find readings difficult to interpret. The study concluded that "there was little indication that participants were using self monitoring to effect and maintain behavior change".

### *2.2.1. Compliance vs. Adherence*

"Patient adherence refers to the extent to which a person's actions or behaviour coincides with advice or instruction from a health care provider intended to prevent, monitor, or ameliorate a disorder" (Christensen, 2004). The term "adherence" is used in behavioural science literature and in nursing psychology literature and the term "patient compliance" is used in medical literature. The term "compliance" minimizes the patient's role in decision-making and "patient adherence" is considered the outcome of a patient-provider relationship in which engages the patient's perceptions and intent (Eisenthal et al., 1979).

Adherence is an interactive process; many components are interrelated and will influence the individual's behaviour. For satisfactory self-care adherence the patient has to have knowledge and skills, belief, motivation, action, and feedback. A breakdown of any of these components may lead to non-adherence (Gerber & Nehmkis, 1986).

### ***2.2.2. Determinants of Patient Adherence***

In order to improve a patient's health outcomes and quality of life with type 2 diabetes it is necessary to understand why non-adherence occurs. Results from various studies (Ratner, 1998) indicate that poor treatment adherence is related to poor health outcomes. Identifying the determinants of non-adherence is crucial in understanding why this problem is so prevalent. Our understanding of all the factors and how they relate with each other is still modest. Six categories of potential determinants will be discussed:

- a. Regime complexity
- b. Treatment cost
- c. Patient socio-demographic status
- d. Patient's psychological factors (locus of control, self-efficacy)
- e. Social support
- f. Provider characteristics

#### ***2.2.2. a. Regimen Complexity***

Generally, the more complex the treatment regimes are, the poorer patient adherence is (Meinchebaum & Turk, 1987). In the case of diabetes management, patients are faced with many responsibilities, taking medication or sometimes insulin, self-monitoring glucose levels a few times a day and monitoring and adjusting dietary behaviour as well as physical activity every day and for some either taking medication or insulin (Cox & Gonder-Frederic, 1992). There are other self-care activities involved, including being vigilant about injuries to the hands and feet, being aware of physical changes due to fluctuation of glucose levels (hyperglycemia and hypoglycemia). It is not

surprising that non-adherence rates in diabetes are among the highest of any patient population. Patients show poor adherence to some aspects of the treatment regime while maintaining adherence in other areas (Orne & Binik, 1989).

#### *2.2.2. b. Treatment Cost*

Studies that investigated treatment cost have different results (Tjia et al., 2008, Tseng et al. 2008, Grant et al. 2006., Reichert et al., 2000, Chisholm et al., 1999). Some showed that treatment cost is a significant barrier to patient adherence (Reichert et al., 2000). Tseng et al. (2008) found cost-related medication underuse in diabetes patients, that was more prominent in racial/ethnic minorities and low income patients. Tjia et al., 2008 explored “unvoiced concern” of older adults with type 2 diabetes and how many patients did not bring up concerns about medication cost or their desire to reduce medication burden, and easily talked about adherence and side effects. Chisholm and colleagues (1999) showed that if the medication was provided free of charge adherence was improved over a short period, but would then go down despite that the medication was offered at no cost.

#### *2.2.2. c. Patient Sociodemographic Status*

Demographic factors such as being an ethnic minority, of low socioeconomic status, and having low levels of education have been associated with lower regimen adherence and greater diabetes-related morbidity (Delamater et al., 2001). There is some evidence that males exhibit poorer adherence than women (Lloyd et al., 1993).



#### 2.2.2. d. *Psychological Factors*

Psychological factors are connected with regimen adherence. Psychological problems such as anxiety and depression have also been connected with inferior diabetes management in both youths and adults (Delamater et al., 2001). The new DAWN study showed that a large number of patients with diabetes have poor psychological well-being and that health care providers reported that these psychological problems negatively affected regimen adherence (Peyrot et al., 2005). This study also illustrated that many health care providers do not feel convinced of their ability to identify psychological problems in their patients and to provide the psychological support their patients need.

**Locus of control:** Locus of control is theoretical construct designed to assess a person's perceived control over his or her own behaviour. The classification *internal locus* indicates that the person feels in control of events; *external locus* indicates that others are perceived to have that control.

For decades, the locus of control construct has been mentioned often in the diabetes literature. The general locus of control construct was modified (Rotter, 1966) to reflect more health related outcomes. Association between the locus of control and adherence behaviour is still undecided (Wallston, 1992). Some studies show that that internal locus of control predicts more positive adherence (Chen et al., 1999; McDonald-Miszczak et al., 2000). Nevertheless, other studies showed that internal control is not directly related to adherence (Graveley & Olseaseon, 1991; McNaughton & Rodrigue, 2001).

**Self-efficacy:** Self efficacy is a central construct of the Social Cognitive Theory (Bandura 1986; Bandura, 1989), that refers to a patient's belief in him/herself to engage

in behaviour whose purpose it is to reach a positive outcome. Self-efficacy beliefs predict success with the maintenance of exercise and diet regimes (Ewart et al., 1983; Ewart, 1992; Jeffery et al., 1984). Self-efficacy and the locus of control are two constructs that can be joined together to best predict patient adherence. (Christensen, 2004; Kaplan et al., 1984).

#### *2.2.2. e. Social Support*

Family relations play an important role in type 2 diabetes management. Studies have revealed that high levels of cohesion and organization, low levels of conflict, and good communication patterns are linked with better regimen adherence. (Delamater, 2001). Better levels of social support are linked with better regimen adherence (Glasgow & Toobert, 1988). Social support also serves to buffer the adverse effect of stress on diabetes management. (Griffith et al., 1990).

Göz and colleagues (2007), found that male patients, retired patients and patients that lived alone had a high quality of life score and also perceived a high level of social support. They observed that “If perceived social support and quality-of-life were increased together, it means that social support increases quality-of-life.” They suggested that this association could be important to clinical practice and that enhancing social support in type 2 diabetes, may lead to better metabolic control, self management and psychosocial modification.

#### *2.2.2. f. Provider Characteristics*

Patients with the social support of a nurse have been affected positively by the health care provider's promotion of adherence to diet, medications, SMBG, and weight loss (Sherbourne et al., 1992). Aubert et al. (1998) showed that having regular contact with patients by telephone promoted regimen adherence and achieved improvements in glycemic control as well as in lipid and blood pressure levels. The Diabetes Control and Complications Trial also showed that one of the key elements to success in achieving good glycemic control was the availability of support provided to patients by the health care team (The DCCT Research Group, 1995).

Understanding the context to which these factors support or hinder success in treatment is incomplete. Not only is knowledge of the effects of single factors incomplete, but there is little information on the combined effects of multiple factors which might influence the situation of patients at once. Without more integration, it may be difficult to increase the effectiveness of treatment which relies on environmental and behavioural factors.

### **2.3. Patient-centered Approach**

Some authors believe that the solution for type 2 diabetes lies in moving from adherence and compliance to patient empowerment. Anderson and Funnell (2000) further explained that: "For diabetes care to succeed, patients must be able to make informed decisions about how they will live with their illness." They believe that physician-oriented or compliance-oriented care is not an effective approach and that the patient has to have intrinsic motivation to be able to set their goals regarding self management

according to their personal life and situation at home, as well as family demands and priorities. This is a patient-centred approach which leads to a partnership between health care providers and patients, and may eventually replace non-compliance as the approach to this problem.

Qualitative studies can play a role in understanding the patient perspective. This study has been done to reveal the different aspects of life with the disease including the obstacles to better management and the cost of having the disease (monetary, emotional and social cost).

#### **2.4. Influences on Food Behaviour in Diabetes Management**

Canadian Aboriginal and many indigenous people perceive their health through land and culture (Knudson, 1992; Suzuki, 1992; Lindheim & Syme, 1983). Melbourne Aboriginals view diabetes “as a result of living life out of balance, a life of lost or severed connections with land and kin and a life with little control over past, present or future.” It is seen as a condition imposed from the outside as a consequence of the disruption of the native way of life. They perceive that not only glucose levels are out of balance but that their whole lives are out of balance too. The central role in Aboriginal social life is the family and extended kinship system and little significance is placed on individual possessions. Melbourne Aborigines describe that exercising is being ‘selfish’ and dishonorable because it can disrupt family connections. Losing weight is viewed as disruptive for the family balance, because it involves the preparation of separate meals and places a burden on the family. They see their commitment to family and community as more important than regular management of their diabetes. This study showed that the

self-perceived health of Melbourne Aboriginals is complex, and that “individual behavior is woven into broader systems of family, community and society (Thomson & Gifford, 2000).

A study was done in an isolated Ojibway-Cree community, where authors described type 2 diabetes in conjunction with socio-cultural concepts, as well as an original belief system which influences dietary behavior (Gittelsohn et al., 1996). Food was perceived as “Indian”—healthy and “White man’s”—unhealthy and type 2 diabetes is seen as the result of the consumption of White man’s junk foods, and there is a belief that the disease can be avoided by eating traditional foods. Exercising to control obesity and decrease the risk of diabetes is not accepted.

The traditional Aboriginal food consisted of grains, squash, melons and legumes, meat, fish, wild greens, berries, vegetables and fruit (Health Canada, 1995). The Aboriginal population has adopted a typical Westernized diet which is high in animal fat, simple carbohydrates, and contains less fiber. Studies suggest that the adoption of an Anglo diet increases the chance of developing type 2 diabetes in Pima Indians, and that “obesity is less prevalent among people of Pima heritage living in traditional conditions on the land than those living in an ‘affluent’ environment.” These studies propose that that in spite of genetic predisposition, a traditional lifestyle (low fat diet and physical labor) may protect against development of obesity and type 2 diabetes (Ravussin et al., 1994).

The problem lies in describing the factors, or determinants, in such a way that they can be used to explain the lifestyle choices of Aboriginal patients. The combined

influence of a variety of factors needs to be documented in the context of Aboriginal culture.

## **2.5. Lifestyle Choices in People With Type 2 diabetes**

This study examines lifestyle choices in people with type 2 diabetes; a review of interview-based studies is suitable. It is difficult to find a common base of knowledge in all these studies because they investigated the problem from different perspectives and used different methods. Various themes are recognized and highlighted. I found that a few studies influenced my work and they will be looked at here to some extent.

There were several studies done in Manitoba regarding type 2 diabetes within the Aboriginal population and they attempt to account for the staggering prevalence numbers previously mentioned. There are a few studies which explore the life experiences of those with the disease in the urban Aboriginal community; although the research does suggest that there is a definite need for a better understanding of issues that are important to urban Aboriginals versus reserve Aboriginals. “First, the focus on urban Aboriginal Canadians is much needed in Aboriginal health research” (Iswasaki & Bartlett, 2006).

Many of these studies were examining stress levels in relation to living with type 2 diabetes as an important factor in determining how to better explain the living experience of Aboriginal patients. It has been broadly recognized that stress is a crucial element of life for Aboriginal patients. Green, Hoppa, Young, and Blanchard (2003) designated that its prevalence is “tightly embedded within a context of poverty and disempowerment” based on their findings about the prevalence of type 2 diabetes in Winnipeg.

The causes of type 2 diabetes were described as related to factors like marginalization and poverty (Kraut et al., 2001) and were put together in a larger context and seen by many researchers through the lens of historical, cultural, economic and political perspectives (Boston & colleagues, 1997; Thompson & Gifford, 2000; Bruyère & Garro, 2000; Eyles & Upshur, 2000).

In a study that examined stress among Aboriginal women and men with type 2 diabetes in Manitoba (Iswasaki et al., 2005), consideration is given to the meaning of stress, and major causes of stress in people's lives. Many common themes were identified (the physical stress of managing diabetes, fears for the future, suffering from complications, the financial aspects of living with the disease, economic conditions (poverty, unemployment), deep rooted racism and identity issues. These themes were not recognized as mutually exclusive, but as entwined.

More recently, investigators have explored resilience in Aboriginals in a cultural context. Walters and Simoni (2002) talk about the "cultural resilience" of Aboriginal women who used coping strategies like spiritual coping, traditional healing and enculturation. Within the context of their study, Iswasaki and Bartlett (2005) explore a new dimension of "woundedness" and contrast it with "resilience" to capture both sides of the coping strategies that are employed in the unique cultural context of being Aboriginal and having type 2 diabetes. They discussed stress (an element of woundedness) and coping with stress (human strengths and resilience).

In their conclusion they argue that "Perhaps living in an urban setting may create an additional source of stress, unique to urban dwellers, compared to Aboriginal individuals who live in a non-urban (i.e., rural, on-reserve) setting."

In their study, Gregory and colleagues (1999) found three common themes: “diabetes as omnipresent and as an uncontrollable disease”, “beyond high sugar: diabetes revealed in bodily damage” and “the good, the bad, and the unhelpful: interactions with health care providers”. This research supported previous research in finding a pan-Aboriginal model of diabetes that could be used in treatment and prevention programs for Aboriginals living with the disease.

Patients talked about similar issues in other studies (Thomson, 2000; Parker 2002; Hjelm, 2005) that were done outside Canada. I am using these references to show that there are common cultural experiences shared between different geographical areas. There were some interesting common findings that connect many diabetes patients’ perspectives into a sheared catalogue of diabetes experiences. Therefore, similar cultural experiences may be very influential in understanding type 2 diabetes patients.

Thomson and Gifford (2000) examined wider contexts as well as people’s understanding of their diabetes. They focused on the risk factors and the meaning of diabetes in an urban Aborigine community in Australia. They used an ethno-epidemiological approach, which is a holistic approach that moves away from the individual and universal-based approaches to chronic disease epidemiology. The advantage of this approach was to “enable a more sophisticated and comprehensive understanding of risk which allows for the identification of factors that reflect people’s own construction of their social worlds through naturalistic observation” (Thomson & Gifford, 2000).

Thirty-eight in-depth interviews were conducted, with males and females ages 20 and up diagnosed with type 2 diabetes, as well as some cases without diabetes. The



methods of data collection included: participant observation, informal interviews, focus group discussions, and in-depth interviews. They were guided by a theme list (the meanings of food and physical activity in people's daily lives, and two sections that draw explanatory models of type 2 diabetes and health).

Interviews and focus group discussions were analyzed using content and thematic analyses. Results showed that Aboriginal participants saw the problem of "sugar" as a disruption of balance. "Sugar runs in the family" has positive and negative meanings (it connects or disconnects). "Sugar" is a cultural food passed down through the generations and has a connection to the family identity through time and environment. It makes people vulnerable and is viewed as a possible reason for a disconnection with the land, culture and past. The data showed that men and women acted differently. Investigators found that men ignored the disease more often after they were diagnosed because they originally had more connections to land and family; since they had lost their land, the only symbolic connection left to them is sharing a family meal. It is impossible for men to have that connection, because women still play a central role in preparing meals.

Aboriginal participants talked about the problem of "sugar" as a disruption of balance, leaving the body open to illness. They become susceptible because they "worry" about moving, separation from the family, a lifestyle with alcohol and unemployment. All these factors leave one open to disease. Additionally, eating diet foods instead of family food (which is described as "rich", "nourishing", "filling", and "satisfying") and exercise for one's individual health (seen as "selfish" and "shameful") further detaches one from their family and community.

Home-cooked meals (red meat with fat is seen as “life-fulfilling”) and fast food meals shared with the family have a special meaning which causes people to protect the tradition even though it may be unhealthy. Health is seen only in the context of the larger family and community, and disease as a result of isolation and disconnection with the land and the family. The role of the family can cause additional stress in terms of obligations which can cause disease. Stress is increased by medical advice to lose weight which obliges them to prepare separate meals, and at the same time body size doesn’t have an impact on one’s status in the community but becomes a problem when it is labelled by medical doctor as such.

Type 2 diabetes is seen as an acute disease that comes and goes and participants talk about it in the present because they don’t have any control over the future of the disease. They forget to take their tablets because of their obligations to their family. They talked about “difficulties in managing their sugar levels because in part, the unpredictability of sugar levels is like the unpredictability of life in general” (Thomson & Gifford, 2000). Owing to this unpredictability, the attention necessary for type 2 diabetes management is seen as impossible.

The family and extended kinship system remain essential to the Aboriginal social life as little importance is placed on individual ownership and property. They argued that the problem of the disease should be seen in a broader social, cultural and political context and not primarily as an individual responsibility.

Thomson and Gifford showed that “the understanding of risks and the experiences of the illness itself cannot be separated from people’s experiences of the unstable, unpredictable and disempowered realities of everyday life.

A study involving 10 Native Americans with type 2 diabetes explored the experience of Native American Indians (Parker, 1992) using a phenomenological approach to gain a cultural understanding of type 2 diabetes. The study, conducted in the Appalachian region, West Virginia (Tessaro et al., 2005), showed a lack of knowledge about type 2 diabetes and no perception of its risks. Having the disease negatively shaped social interactions. Six categories were found and synthesized into descriptive structures. Choices to adapt to the disease were a reaction to the diagnosis: decisions to delay modify and comply with the regimen, identification with other Aborigines with type 2 diabetes, due to strong cultural ties and characteristic responses to the loss of health. A strong sense of grief was found through the transcription process that was not recognized by the participants.

There were 73 female and 28 male participants, identified as white, who were interviewed through focus groups. The disease was seen as a result of lack of self-discipline and laziness, and blame and guilt were associated with the diagnosis. A common belief was that it struck every other generation in a family and that people didn't want to know that they had the disease because they didn't want to burden their family. They talked about their fear of type 2 diabetes complications, especially blindness and amputation. "I think it is worse than cancer. I put it higher than cancer, because it is long term. It is slow process of dying. Where cancer seems to be more quick...where cancer, I hate to say, it's not short and sweet. It's just short."

They lacked knowledge in many areas: diet, physical activity and resource information. They felt that they caused the disease, and that the responsibility to control it was completely theirs. They expressed their belief that doctors have little knowledge

about nutrition and that they assumed that some people have the money to pay for expensive diets and equipment. The cost of care was a major concern; health-related decisions are made related to socio-economic factors and the level of poverty. “Decisions about early detection of diabetes and care-seeking are frequently made from the integration of cultural values with the pervading poverty” (Tessaro et al., 2005). They expressed feeling depressed because others didn’t understand how the disease was affecting them. They didn’t want to be treated differently but felt that others didn’t understand what they were going through. Self-blame negatively affects social relationships. People with the disease are blamed for it because of society’s impression that having it is their fault, which affects them negatively and creates a stigma.

Previous studies of beliefs about type 2 diabetes focused on how people experienced living with the disease and the causes and explanations for it. One of the studies, (Hjelm et al., 2005) which was done in Sweden, focused on the beliefs of men of various ethnic origin with the illness. They compared participants born in Sweden and immigrants who lived in Sweden (who were born in former Yugoslavia or in Arabic countries). They found a variation in beliefs about health and type 2 diabetes that influenced self-care behaviour. Being employed and having knowledge about the body and management of the disease was found to be important. They found that there is a need to raise awareness about the importance of employment and economic factors in preserving health in people with type 2 diabetes.

All mentioned qualitative studies were looking into different aspects of living with the disease. There are no studies focused specifically on comparing the Aboriginal

and non-Aboriginal population in relation to how they perceive control over and cost of their illness in the broader context of an urban centre like Winnipeg.

## 2.6. “Lifestyle” Critique

This thesis is about lifestyle choices among a group of people with type 2 diabetes and it is likely that these people talk about “lifestyle” and have different things in mind (Bandura, 1984). Lifestyle choice is explained by health researchers (medical science and psychologists) as “people’s day to day habits and behavior patterns” (Henderson et al., 1980) and they are interested in behaviour change programs. The view of public health scientists and social medicine specialists differs because they believe that lifestyle associates with living conditions and they are interested in identifying populations at risk, and strengthening social and personal resources.

The medical model of health and disease emphasizes that lifestyle plays a central role in the genesis of important disorders (myocardial infarction, lung cancer, and diabetes). Many scientists understand human behaviour in terms of habits and that those individuals choose the way they behave, and that it is their own responsibility and fault if complications arise. They also believe that health education should consist of changing people’s level of consciousness (Paul, 1982).

The concept of lifestyle was initiated in 1974 in a publication “A New Perspective on the Health of Canadians” (Lalonde, 1974). This document was among the first to recognize lifestyle as a determinant of health and illness. Lalonde defined lifestyle as:

*“The aggregation of decisions by individuals which affect their health, and over which they more or less have control. ... Personal decisions and habits*

*that are bad, from a health point of view, create self-imposed risks. When those risks result in illness or death, the victim's lifestyle can be said to have contributed to, or caused, his own illness or death." (p. 32)*

The new World Health Organization definition of lifestyle (WHO, 1998) has begun to consider the influence of social, economic, and environmental factors on lifestyle. "Healthy lifestyles include a wide range of behaviors, such as effective coping, lifelong learning, safety precautions, social interaction, volunteering, parenting, spirituality, balancing work and family, as well as good nutrition, physical activity, safe sex, and avoiding tobacco and substance abuse"( Lyons & Langille, 2000).

In their report on healthy lifestyle: "Strengthening the effectiveness of lifestyle approaches to improve health" Lyons and Langille explained many factors which determine lifestyle choices by examining the context of community norms, the broader social and economic conditions and that people make choices according to their life circumstances but not from the perspective of healthy choices, per se. An important conclusion was derived: "The causes of health and disease are a complex interplay between individuals, social structural factors (i.e., SES, educational attainment and occupation), cultural factors (e.g., the health beliefs of various ethnic communities and peer subcultures) and exposures to particular risk and protective factors".

Epidemiology is the main supplier for the basis of action for preventive medicine and health promotion (Forde, 1998). The Norwegian psychologist Skolbeken has publicized that "risk epidemics" has its roots in medical journals (Skolbeken, 1995). He suggested, "risk epidemics" reflect the social constriction of a particular culture in history. The German sociologist Beck, described modern society as a risk society (Beck,

1992). People are constantly conscious about environmental risks to human health from air and water pollution. People tend to overstress and overreact to medical risks. A person obsessed by risk is socially impaired, and a completely controlled, risk free society has few supporters (Forde, 1998).

Lifestyle factors may not be viewed as controllable (Nettleton, 1995). For example, Davison et al. (1992) in anthropologic study of health beliefs during the Heartbeat Wales campaign found that ideas about the influence of lifestyle on individual health are related to aspects of life that cannot be controlled by individuals. Four aspects of life were identified from informants: self-evident personal difference (e.g. hereditary factors); social environment (e.g. occupational risks and loneliness); physical environment (e.g. climate, and pollution) and fatalism (e.g. bad luck and personal destiny).

This concept of luck stands in opposition to the notion of risk. Davison argues that the claims of health promoters are based on predictability and certainty and that they are counter-productive as they don't fit with beliefs that are found in popular culture (Davison et al., 1992). Laypeople do not passively accept medical ideas, and if they don't fit into their plan they may be ignored and rejected (Baxter, 1983; Calnan, 1987). Conrad, in his study of wellness in the workplace explained the limitations of prevention: "just because behavior is a 'risk factor' doesn't mean automatically that change will lead to corresponding change in health" (Conrad, 1987). He argued that the overwhelming focus of work-site health promotion on individual lifestyles "muddles the reality of social behavior", including class, gender and race. It doesn't include improvements of working

conditions, and rarely involves discussing occupational disease or hazardous working conditions.

The relationship of social class to the acceptance of epidemiological facts is obvious. Social class remains the single most potent determinant of morbidity and mortality (Townsend & Davidson, 1988), and it is often treated as a potential confounder (Forde, 1998).” The “lifestyle” approach enables the population to acknowledge and change the problem of the social environment (Backer, 1986).

The association between the public health movement and the middle class mortality rate is not new (Lupton, 1995). The whole health promotion concept has a middle-class bias (Minkler, 1985). There is a tendency of clustering “bad” habits among lower social classes, and declaring upper class habits as healthy (Forde, 1998). Scientific clarity and moderation manifest the superiority of one’s own lifestyle (Johnstone, 1991).

Traditionally, a prospective life perspective for the middle class is a struggle for self-control, life control, and prudence associated with Protestant ethics that band middle class values (Weber, 1973). Lower social classes have focused on the present and risk-taking behavior was predominant.

In the 1980’s, health activities were seen as increasing individual health and reducing the risk of disease. Not smoking, low cholesterol diets, and regular exercise can reduce the risk of heart disease. In modern society the religious component is replaced by healthism (Conrad, 1992). Health promotion is responsible for the new health morality, and the process is similar to medicalization, but because it fuses both medical and behavioural problems it is conceptualized as “healthism” (Crawford, 1980). With healthism, behavioural and social definitions are advanced for previously biomedically



defined events. Healthism is defined as “a preoccupation with personal health as a primary focus for the definition and achievement of well being, a goal which is to be attained primarily through the modification of lifestyles, with or without therapeutic help” (Crawford, 1980).

The formulation of healthism is based on the individual mind and body and is an ideology which includes the self-reconstruction of attitudes, emotion and behaviour, or the intervention of healers. The problem of individual responsibility becomes highly problematic and it creates the illusion that individual responsibility is sufficient. It promotes the concept of control over the powerlessness experienced by the patient. “I can’t change the world but at least I can change myself” (Oyle, 1979).

Healthism has a very specific, new morality that blames individuals for their behaviour. In healthism, healthy behaviour has become a paradigm for good living. It reinforces the false impression that individual coping is enough, and the possibility of changing society by changing oneself.

Those most able to make individual adjustments are more likely to be middle class. This religion and morality represents cultural unification and may lead to cultural imperialism (Forde, 1998).

## **2.7. Summary of the Literature Review**

This literature review is designed to gain a better understanding of the scope of type 2 diabetes as a growing public health problem, what research has done to illuminate the issues regarding patient compliance and adherence, a critique of the lifestyle choice

movement, and a review of the type 2 diabetes qualitative research studies done in the past.

The first theme discusses type 2 diabetes; its prevalence in Manitoba (specifically in the Aboriginal community) and its management. It looks at the complex factors that promote or hinder patient compliance to treatment on the individual level. It is followed by an in-depth look at the reasoning behind lifestyle choices.

The second theme investigates disease and its management. Educators and health care providers often hold contrasting or conflicting views to those of their patients. The understanding of the reasons that people have for their behaviour (food choices, exercise and social life) are influenced by many factors.

All these factors have different meanings for each individual and help to form their unique decision-making process (what to eat, how much to exercise and how and with whom to socialize). Food choice is one aspect of human behaviour that utilizes all cultural, social and individual aspects of human nature and is a good method to use to be able to better understand the deeper subconscious meanings that influence one's lifestyle choices and behaviour.

The next themes looked at interview based studies and their results on the complex reasons that people have for their behaviour, and how the Aboriginal population experiences living with diabetes. Their unique perspectives on the management of diabetes were also considered.

The patient with type 2 diabetes is a part of a society with certain values that will influence him greatly. The lifestyle movement made type 2 diabetes patients responsible to their own wellbeing. As a result the patients are put in a position where they can be

judged and blamed for their decisions. The biomedical system locates responsibility to illness in the individual and has authoritarian values where patients either adhere or comply to treatment options or do not. This may be putting a lot of strain on patients who have to deal with the disease symptoms and attempt to balance their lives accordingly. This puts the patient in the centre of certain cultural influences; societal values, health care values and his own relationship with the disease in relation to influence. Qualitative studies have potential to unable better understanding of the position of the patient and his view of the disease and the reasons behind his lifestyle choices.

This study is based on interviews with the Aboriginal and non-Aboriginal population in central Winnipeg. The study focused on their food and exercise choices and the relative costs for living with type 2 diabetes. The outcome of interest to this study is the documentation of the reasons behind individual lifestyle choices, and the relative costs that type 2 diabetes patients experience in dealing with common environmental determinants. It is probable that comparisons will have to be made between the Aboriginal and non-Aboriginal population. It will compare how they perceive the association between their lifestyle and their ability to control their disease.

## **CHAPTER 3: METHODS**

### **3.1. Research Design**

#### ***3.1.1. Research Question***

What are the perceptions of people with diabetes of the social, economic or psychological costs experienced as a result of living with the condition?

#### ***3.1.2. Objectives***

1. Documenting the reasons why some patients with type 2 diabetes feel that they are in control of their diabetes, and others do not.
2. Documenting the reasons that individuals have for their lifestyle choices, including food choices, physical activity, and a range of social behaviours.
3. Documenting the relative cost that patients experience in dealing with common environmental determinants that act as barriers to improving their health.

Of additional interest are the possible differences between population groups represented in the sampling frame for the study, in particular the experiences of the Aboriginal and non-Aboriginal populations.

#### ***3.1.3. Population***

The data were obtained from follow-up patients attending Diabetic Clinic at one of the community clinics in the centre of Winnipeg. Follow-up patients were defined as people with type 2 diabetes who had at least one education session. The process of selection for patients ensured equal numbers of patients of Aboriginal and non-Aboriginal background.

#### **3.1.4. Data**

The primary data consist of the perceptions, beliefs, and attitudes of patients associated with the aspects of daily living that are important to them, including their response to diabetes, that are categorized using constructs developed by Ajzen & Fishbein (1980). The data extends into descriptions of the lifestyle choices that patients make, including dietary behaviours, and the reasons for these choices.

The data are collected through an integrated in-depth interview and visual food frequency record. The combined interview and food frequency allows patients to express the links between their perceptions and behaviours, rather than an interpretation of these links by the researchers from two separate records.

Data analysis starts by applying the technique of content analysis for qualitative data that identifies the different aspects of the patient's life, including the reasons for their behaviour (Glaser, 1978; Straus & Corbin, 1990). Content analysis is the recognition of constructs in the transcripts of interviews that capture direct and latent meaning. Differences in the frequencies with which constructs occur in the explanations of patients will be used to understand the relative importance of patient choices. Results will be combined with social and economic status data from a demographic questionnaire, in order to interpret the data in the context of the research question and the three objectives.

### **3.2. Methods and Materials**

#### **3.2.1. Subject population:**

The sampling frame was the patient group attending Diabetic Clinic at one of the community clinics in the centre of Winnipeg. The sample was a purposive sample of the

patients that met predefined selection criteria. Participants were selected from follow-up patients at the Winnipeg community clinic, who were defined as people with type 2 diabetes who had at least one education session regarding recommended dietary and health behaviours in dealing with type 2 diabetes. Inclusion criteria were:

- Older than 18 years
- Able to communicate in English
- Attended at least one education session

All patients meeting the inclusion criteria were asked to participate by clinic personnel, until a total of 17 self-identified Aboriginal patients with type 2 diabetes and a total of 21 non-Aboriginal patients with type 2 diabetes of varying ethnic backgrounds had agreed to participate. There were 19 refusals. The demographic characteristics of patients attending the HAC varied, and included different age groups, socio-economic groups, urban, rural and reserve living conditions, as well as patients who had moved from rural or reserve areas to the city.

The sample size was based on the observation of saturation of constructs in the interviews. The majority of constructs, and linkages between constructs, were identified by the 13<sup>th</sup> or 14<sup>th</sup> interview in each group. No new constructs were identified after the 16<sup>th</sup> interview in the non-Aboriginal group. The sample size was therefore seen as adequate for the purpose of this study.

### *3.2.2. Pilot Interviews*

Prior to data collection, five individuals known to the researcher were asked to complete both the Food Choice Map interview and the demographic questionnaire. The total time to complete the two instruments was approximately one hour for each patient.

The data were used as a pilot study of the interview question guide, procedures, and questionnaire. Following this pilot test, the materials and procedures were revised to deal with potential problems of communication during the data collection or interpretation of data during analysis.

### ***3.2.3. Recruitment of Participants***

The front desk assistant at the community clinic contacted participants over the phone, explained the study, obtained a verbal indication of interest on the part of the patient and contacted the researcher with the names and contact information of patients agreeing to participate.

All 38 interviews were completed during a period of two and a half months. Most interviews that were scheduled were done on time; therefore the researcher was able to have two to three interviews per day. This was only possible because of the highly organized and caring staff that was able to communicate fast with the researcher and to make changes in planning. The researcher had a room that was very quiet that made people comfortable to talk and it was easy to lead interviews without any distractions, noise and interruptions.

### **3.3. Data Collection**

Thirty-eight people were interviewed. Interviews were recorded (using a tape recorder) following consent by the interviewee. Data were collected using demographic questionnaire and a Food Choice interview.

### ***3.3.1. Demographic Data Collection***

Every interview started with completion of the demographic questionnaire that lasted about 15 minutes. The demographic questionnaire was designed to collect information on the patient's age, education, skills, working experience, and expenditure categories for major living costs, housing transport, and food. Interviewer assistance was available as required. The questionnaire is found in Appendix on page 122. The interview was conducted after the respondents completed the demographic questionnaire.

### ***3.3.2. Food Choice Map Interview Data Collection***

The Food Choice Map (FCM) interview is an integrated semi-structured interview that took approximately 40 to 45 minutes to complete. The Food Choice Map is an interviewer administered in-depth interview. The question guide includes prompts related to food, exercise and lifestyle behaviour, with an emphasis on the reasons that individuals have for this behaviour. The interpretations are centered on the reasons that imply effort on the part of the individual to maintain current behaviour or start new behaviour (Sevenhuysen, & Gross, 2003).

The Food Choice Map was developed to record food choices and the reasons for them. During the in-depth interview, the respondent participated in making a visual representation of food patterns during a usual week. The interviewer then used the information on the 'map' to prompt for related behaviour, and extended the discussion into other areas of experience and interest. The technique maximized the understanding between the interviewer and the respondent about behavioural patterns and the reasons for them.



### ***3.3.3. The Food Choice Map Interview***

The process of creating the Food Choice Map started with the interviewer asking about commonly eaten food. Interviews were conducted in the same meeting room at Health Action Centre and one interviewer conducted all interviews. The interview started with a model of map. The horizontal scale on the map has the numbers from one to seven, which refer to the approximate weekly frequency of consumption of food items. The vertical scale of the grid allows the respondent and the interviewer to show time periods during the day that food was normally eaten in the empty margins to the left and right of the grid. The initial stage of the interview consisted of questions and answers, which developed into conversations. This created a visual map of personal food intake. To start the process, the respondent was asked to name the food(s) that were eaten most often. Next, other foods were named and associated with meals or time of eating. For each food choice the interviewer placed a small magnetic sticker with a generic picture of the food in the margin of the grid.

The interviewer then continued with a series of interactions to find the relative frequencies with which each of these foods was eaten during a usual week. Each time, one of the stickers of food was moved horizontally into the grid, to a position that showed how often in a usual week that food was eaten and moved vertically to reflect the mealtime. E.g. breakfast or lunch. During the process the interviewer encouraged the respondent to move the stickers personally, especially when double-checking that the frequency of stickers already in the grid was correct. In this way the respondent took an active role in creating the map of his/her own food choices.

The next stage of the interview was a conversation regarding the circumstances in which the respondent ate the foods shown on the map. Socially related information was included: with whom foods were eaten and where (such as household members, colleagues at work, special occasions and other social context). Economically related information included the number of income earners in the household, who contributed to food expenses, who controlled food purchases, the shops or other places where the household obtained food. Information related to the personal living environment included transportation used to get food, opportunities for storing foods, which food were more important for health, what sources provided reliable information on food. Many of the aspects that the respondents regarded as important were elicited by asking why the respondent ate a particular food more often than another, or why a food could substitute for another. Direct questions were avoided.

Answers were recorded using colour-coded lines to circle food pictures associated with the same answers, notes in the margins, and or records on a separate sheet. The questions and answers were tape-recorded.

### **3.4. Ethical Considerations**

The University of Manitoba Health Research Ethics Board approved the procedure for contacting respondents and completing this research project. Every respondent signed a consent form (see Appendix p.128) before the researcher started interviewing. The researcher used pseudonym names for the patients through the whole thesis.

### **3.5. Data Analysis**

The in-depth interview records were transcribed verbatim by researcher. Data analysis started with the researcher reading the transcript and underlining constructs that could be of interest whilst keeping the study objectives in mind: a) reasons for being/not being able to control diabetes, b) reasons for food choices, c) cost (monetary, social, emotional). All comments were underlined and written on the margins of the transcript for the first time.

The next stage of data analysis used content analysis to identify constructs in each transcript that each respondent expressed in the interview. Content analysis is a research technique for making replicable and valid inferences (or other meaningful matter) to the context of their use” (Krippendorff, 2004). Content analysis is good method to describe key issues of particular group of people. “It is useful method for answering questions about the salient issues for particular group of respondents or identifying typical responses.” (Green Thorogood, 2004 ). First step is to read and reread the content (developing an intimate relationship with data) (Ulin at al. 2005). Lists of codes are developed to identify key themes and they are then labeled into codes. Codes are defined and tables of codes were made to be able be to apply them consistently to all transcripts.

The researcher read over highlighted sentences and tried to understand them better and categorize them by page number on a separate sheet in order of objectives (coping/control, food choices and cost). In this data analysis step the researcher identified major themes.

Next, the researcher wrote down (on a separate piece of paper) the key phrases from the respondents’ transcripts. This was done to capture the experiences of living with

diabetes and how the affected party talked about it. They define each respondent's personal approach to health and lifestyle issues. The researcher tried to connect the constructs in a meaningful way reflecting the underlying beliefs and reasons why that particular person makes their unique choices in the way that they experience their lives. The key step during this data analysis step was to identify sub-themes.

Finally, the researcher used frequencies of constructs and then listened to the respondent's interviews again to determine the main messages that came from the whole interview. Similarities and differences between the respondents in their approaches to health and lifestyle issues were identified by first finding the most common themes among all respondents. The phenomenon of respondent perceptions and feelings about their diabetes should be emerging from their words.

Participants in this study were asked about their height and weight in the demographic questionnaire. BMI is calculated from the formula:

$$BMI = \frac{\text{Weight (kg)}}{\text{Height}^2(\text{m})}$$

According to Health Canada classification of obesity participants are categorized in obese and non obese categories. (Health Canada, 2008).

Table 1.0 BMI classification table

Classification	BMI Category (kg/m <sup>2</sup> )
Underweight	< 18.5
Normal Weight	18.5 - 24.9
Overweight	25.0 - 29.9
Obese class I	30.0 - 34.9
Obese class II	35.0 - 39.9
Obese class III	>= 40.0

*Note: For persons 65 years and older the 'normal' range may begin slightly above BMI 18.5 and extend into the 'overweight' range.*

BMI classification was used in the results section to be able to understand participants' reasons for weight management behaviour.

### 3.6. Limitations

The information gathered in this study is applicable to patients and services of the community clinic that the participants attended. A number of the study results may be applicable to other patient groups with type 2 diabetes when health care workers who look to increasing their understanding of the responses of their patients and to appreciate the differences that may arise from the different cultural backgrounds of the patients.

It may not be possible to transfer all study results to other patient groups. Trustworthiness is establishing the validity and reliability of qualitative research (Streubert & Carpenter, 1999). Lincon and Guba (1985) state that study is credible when description and interpretation of human experience are such that people that shared same experience can recognize that explanation. Trustworthiness of this study was addressed

by using the four criteria (credibility, transferability, dependability and conformability) identified by Lincon and Guba.(1985)

Data analysis strategies were used to increase the credibility of results. In the process of describing meaning, triangulation was used between: 1) in depth interviews, 2) visual map, 3) review of relevant literature, specifically in the psychological, anthropological, medical areas. In addition, thick description and purposeful sampling are used as strategy to increase transferability. Dependability was improved by consistent use of tape recordings, interviewer notes and external review of the content analysis process and emerging themes for consistency in interpretation of meaning by a qualitative researcher. Conformability was addressed in committee debriefing by experienced qualitative researchers (committee members), assisted researcher to reduce potential biased interpretation.

The interpretation of the data is subject to similar limitations as for many qualitative studies. The primary instrument of data collection, analysis and interpretation is the researcher, and the final conclusions are a result of the researcher's knowledge of the study. The researcher's background (as a physician), gender, age, and ethnicity may have introduced potential biases. Medical training may have made it easier to understand the views of health care providers than patients. As a woman, it is possible that comments from male participants may have been interpreted differently from those of female participants. Similarly, comments of participants closer to the age of the researcher may have been interpreted more easily than those of participants from younger or older generations. As a new immigrant to Canada, the researcher could have interpreted

comments of participants with differing accuracy. During the analysis the researcher took great care to ensure that any bias was negligible.

Lack of information on the diabetes status of the participants may have affected the study. It would be easier to make better correlations and draw possible richer conclusion if there were more information on diabetic status of participants. Age discrepancy between Aboriginals & non-Aboriginals may be affecting study results as well. Fourteen Non-Aboriginal participants were over 66 years old compared to 3 Aboriginal participants.

## CHAPTER 4: RESULTS

### 4.1. Population and Sample

Before explaining how people with type 2 diabetes talked about their management, a brief summary of the participant's culture background, age and education are presented.

The study population in this study is the population with type 2 diabetes in Winnipeg, Canada. Research was conducted in August 2003. The research site was Health Action Centre, located in the core Winnipeg area, one of the poorest parts of the city close to Health Science Centre. Details regarding sample selection are summarized in Table 1.

Table 1.1 Sample selection process

Sample stage	Number
Sample population	57
Exclusions	0
Refusals	19
Final sample	38

The sampling frame consisted of 57 participants from different cultural backgrounds (Aboriginal and non-Aboriginal). There were 19 refusals from people who



decided not to participate in the study, or who did not respond when the researcher tried to make contact, or whose telephones were found to be out of service.

The final sample size was 38 participants, 17 self-identified as having an Aboriginal background and 21 had a non-Aboriginal background. Twenty-one women and 17 men participated in this study with an average age 51 years and a range from 36 to over 66 years. (Table 1.2). This is consistent with the average age for having type 2 diabetes (Statistic Canada, 2001). Details about numbers of participants and age distribution are summarized in Table 1.2.

Table 1.2 Total numbers of participants

Participants in Study	Total
Men	21
Women	17
Age	
18-25	0
26-35	0
36-45	3
46-55	10
56-65	8
66+	17

Education ranged from Grade 8 or less, to postgraduate training. Eleven participants had Grade 8 and less training; 13 had some high school, six completed high school; two had a college degree; four had some university; one had some university; one had a postgraduate degree (Table 1.3).

Table 1.3 Education in study population

Education	Total
Grade 8 and less	11
Some high school	13
Completed high school	6
College certificate or diploma	2
Some university	4
Completed university	1
Postgraduate training	1
Other	0

Seven out of 38 patients were never married; 13 were married, 14 were divorced and four of them were widowed. (Table 1.4)

Table 1.4 Marital status in study population

Marital status	Total
Never married	7
Married	13
Divorced	14
Widowed	4
Total	38

In summary, this is a sample of participants that have type 2 diabetes that attended the HAC in a core area of Winnipeg. The sample included older population (median age 51) which is consistent with incidence of type 2 diabetes. There is diversity in educational backgrounds.

*BMI and the diabetic status of participants*

Table 1.5 Mean BMI

Female	Male
35,4	32,2

Female patients had a mean BMI 35,4 with a range from 33.4 to 39.9. Women were found to be in obesity class one and two according to Health Canada. Mean BMI for men was 32.2, with a range 30, 8 to 33, 6. Men were found to be in obesity class one.

Most patients did not report clinical complications. Two patients had severe complications (amputated limbs). Many older patients live in a residential setting and live alone.

Most of the patients explained that they were on lifestyle programs, but few were on insulin. A lifestyle program is defined as a set of activities that help patients in modifying high-risk behaviours. Patients on a lifestyle program may take medication but not insulin. Most elderly patients mentioned that they have had Diabetes for a long time, and only a few had been recently diagnosed. Only two patients mentioned that they were long-time immigrants. There were no recent immigrants in the study group.

## **4.2. Perceived Coping and Control with Diabetes**

A time-honoured principle of effective coping is to know when to appraise a situation as uncontrollable and hence abandon efforts directed at altering that situation (Janoff-Bulman & Brickman, 1982; Silver & Wortman, 1980a). Individual has to turn to emotion-focused processes in order to tolerate or accept the situation. It is a balance between emotion and rationale-based coping strategies that are used to better deal with situations. Research showed (Lazarus & Folkman, 1984) that most people turn to one predominant way of coping when faced with a threat or a challenge in their life, depending on how they internalize and assess the situation, and depending on their preferred style.

In real life, in the opinion of this researcher it may be difficult to measure effective coping in a valid way. It is obvious that ineffective coping may be seen as depressed patients that are not able to maintain a diet and exercise regimen or to monitor their blood glucose levels. It may be in anger that resistant patients will not comply or won't come to regular meetings. In order to manage their diabetes, patients must be effective in their self-care. This may be a high or impossible standard to meet for most of the patients. A patient deals with their disease on a daily basis. The barriers between regular life and disease management begin to overlap causing a general situational conflict between what is considered to be good for the patient and what he desires. Disease may force a patient to have to adjust to new circumstances constantly as well as creatively. Patients may be struggling for control on every level of their existence, and may use different strategies to cope.

With diabetes, adequate self care plays a pivotal role in management of the disease. Self care is a complex mechanism that requires a patient to be able to use knowledge and to implement it in everyday life. A patient has to be constantly aware of what he is eating, have a good exercise regimen, and be on medication (some patients take oral medication or insulin) and monitor their glucose levels daily. This puts a lot of pressure on the patient who is dealing with physical symptoms and psychological effects due to the diabetes, and at the same time has to fulfill their role in the family and responsibilities to society.

The researcher used this definition of coping to describe patient coping strategies in dealing with diabetes: “it refers to cognitive and behavioral efforts to master, reduce, or tolerate the internal and/or external demands that are created by the stressful transaction” (Folkman & Lazarus, 1980; Lazarus & Launier, 1978). It is a broad definition that gave the researcher a chance to look at the different patients reactions to management of the disease. The strategies that come up in patients dealing with the disease are not seen as effective or ineffective. They reflected a patient’s reactions to disease, their coping and how it fits with their everyday life.

Control is a coping process, which refers to cognitive and/or behavioural efforts to increase a sense of certainty about changes and/or events (Wong & Sproule, 1983). It is seen as part of the coping process and recognized by the level of confidence that patients felt in dealing with diabetes management.

The literature suggests that patients that live life with their diabetes have their own ideas and feelings on various experiences. It seems that patients showed a range of different methods with which they cope with their disease. This might be the way that

disease is incorporated in their own personal and social reality and it is reflected through them in both different and similar ways.

Similarly, this researcher feels that there is a difference in what patients see as a barrier and in managing their diabetes. On one side of the spectrum, patients' fear of the complications of the disease and difficulty in following a diabetic regimen or maintaining their weight were the major issues.

Patients' emotional coping strategies such as fear, anger and physical fatigue that may be barriers to better diabetes control will be explored. Researcher will be looking for ways that they attempt to protect themselves from loss of control

#### **4.3. Objective 1: Diabetes and Perceived Control/Coping**

A continuum of responses to diabetes was seen in the participants of this study. When patients talked about diabetes management some differences between them emerged. They range from patients that feel that they are managing diabetes well, some that feel that they actively manage but feel that there are some problems and then the ones who felt that diabetes management was a real challenge, another burden in life.

When explored more deeply the differences became more subtle and complex and a few themes emerged: "maintenance of weight" and "the physical and emotional burden of diabetes" (fear of hypoglycaemia, depression, fatigue, and tiredness). Evidence will be presented to show that most of the patients reflected on maintenance of weight and expressed some physical and psychological concerns regarding their disease management.

#### ***4.3.1. Maintenance of Weight***

Nine participants explained that they felt in control of their eating habits and exercise regime. In the following paragraphs, examples of explanations from four (non-Aboriginal) participants and from two Aboriginal participants are used to illustrate the experiences expressed among the nine participants.

Most patients in this group appeared to be very concise and to the point and very sure of themselves. They seemed to feel that they did what they needed to do and in general sounded as if they were in a better mood and with more energy than several other participants. These apparent attitudes could explain how they felt able to stick to their daily regimen and to manage their weight most of the time. There is an overall impression that they are actively involved in their self-care, weight and exercise control. They believe in their general knowledge and they said that they implement what they learn and what they think is good for them. They reported that they often pay attention to recommendations from the Centre.

Nigel is a retired Non-aboriginal man who reported that his income met his needs. He is in the 66 and up age category. He lives with his wife and family in Winnipeg. He mentioned that he was diagnosed with diabetes “*a while ago*”.

Nigel is a typical example from this group. He tries to eat healthy. He said his diet contains a lot of vegetables and fruits during the day and fish instead of meat. He is confident that he has been educated enough (“I learn the importance of eating more fish than beef. I stay away from eggs once a week, not even that, what else? It’s important to eat fish and I like it. You can eat whatever you want. You have to train yourself to eat smaller portions”).

He said that when he decides to go on the Weight Watchers diet he will lose his extra weight: “And my weight I wish, I was 10 pounds less. When he asked does he need to lose weight he said “Yeah I keep trying to. And I will eventually, I’ll get serious and take off 10 pounds”. He strongly believes that he is in control of his blood glucose because he exercises regularly: “I am still fortunate that I do that, I walk every day for three miles, I am convinced that it keeps my diabetes more in control and if I can take that ten pounds off then my diabetes would be getting under control”.

It is not always easy to control eating habits, and to manage weight. Nigel admits: “Sometimes I’ll blow it and I’ll have Chinese food for lunch. One day a week...I don’t have a problem staying away from sweet food I do have problem staying away from Chinese food and to control weight. And my weight I wish I was 10 pounds less”. His wife supports him and he decides what they eat during the day. He doesn’t eat food with sugar because he needs to lose weight and he never received advice from the Centre (“No. I didn’t get any instruction here. I once went to dietitian. But I know I want to eat fish and stay away from desserts, basic things.”)

He found a connection between his eating habits and his diabetes control:

*I: Are you planning to change any type of food that you eat now?*

*P: I hope not. My next visit with the doctor, she may be stricter with me and my blood sugar. But ....My blood sugar is about 7.2.*

Nolan is another example of somebody completely sure of himself. He explains it:

*P: “I don’t find it hard. It doesn’t bother me. I can leave it or I can take it, doesn’t make any difference. No anybody that says that its up here (pointing to his head). No it’s easy to stay away from things that you are not supposed to. Ok maybe once in while you take a little bit of this you shouldn’t have but otherwise. No. My sugar levels I test it every day it’s perfect being diabetic.”*

He controls his weight in his own way:



*P: "The only thing I did once when I started putting weight again I use to having lunch and I than lay down turning fat nothing you can do about it. So I quit having afternoon snack and sleep and especially by then I took off 20 pounds in the last month. I was 180 and I was up to 200. The only reason that I can see I was feeding the dog after lunch. So I quit that and now I am back down on 180. Anybody... that'll do it".*

Nina belongs to the 66+ age group and is a Non-aboriginal woman who lives alone and has had diabetes for many years. She is on a lifestyle program. She has an old age pension and mentioned that her income meets her needs. She gets around by car and has a son who lives in Winnipeg.

Nina wants to control her weight so that she can keep her Diabetes in control without taking medication:

*P: "Dr. told me if I lose some weight and walk I don't need to go on medication. I don't need to do that. I try to keep sugar level and keep the weight down. I always knew that I had to lose weight rather than take the medication. I want to lose weight and do it this way".*

*If I am hungry I try to take this I don't have cookies or anything in the house, because I don't bake whatever. When they warn me about sugar I quit baking. I do buy some cookies lemon cookies they are right on a fridge.... But "Simple Pleasure" or something like that that's the name of it. Well I have couple of those sometimes.*

She said that she exercises regularly:

*P: Yee I walk at wellness Centre. Three times a week I walk. They are teaching me some of those machines you know. That would two a week that I would do that. But I try to walk every day at home after supper.*

She seemed in a good spirit, said somewhat laughingly:

*P: My friends says Forget the diet, if you live 75 you eat what you want. I don't go by that. No I don't drink or smoke. No. I never have soft drinks, like coke, cranberry juice, the odd time I have.... I rather have cranberry or water.*

Norman is a non-Aboriginal male in the 56-65 category. He lives alone. He prepares his food for himself. He didn't mentioned how long he had diabetes.

Norman said he was using the information from the Centre and he reported that he feels completely in control. He manages his weight by diet and exercise and sees his dietitian on a monthly basis. When asked whether he thinks that he eats healthy, he replied:

*P: Like I said, most is healthy and like I said I do have a dietitian. I see her every month. (Dietitian) and we do discuss and I try to follow what she says. yaya  
I: Do you find that is hard to follow? No I find it relatively easy to follow. yaa.*

When asked about friends and support system he had interesting comments about how his doctor was his role model:

*P: Mmmm... They have their own lifestyle I have mine.... so I have support My doctor, AND (DIETITIAN) I do have a lot of support there. So when it comes to eating healthy and my doctor he is walking around all the time. Keep that up. I like to see that. I walk every day and I usually walk anywhere 60 at the time, 20 or 30 blocks depend on weather. If it's raining If it's cold the walk is shorter. That what I do for exercises a lot of walking and bike.*

When asked about his glucose levels he mentioned that he was helped by a dietitian and his doctor to regulate his blood glucose levels:

*I: Is it in control?*

*P: We are getting it pretty much stabilizing. It is little over 7- 7,5 before it was all over the place I was 6 and then 17 and next time 11. And no matter whatever I take, o man I am going crazy.... That's I get dietitian involved and I've been with her two years and now my blood sugar is starting to come down and my body is ....(relieved eehh)*

He sounded positive and active. Most patients in this group sounded like they were actively coping with their disease. They sounded as if in a good mood and were interested and involved in the interview process. This group was mostly non-Aboriginal participants; they gave the overall impression that they control their diabetes through their lifestyle choices, weight control, and good general knowledge.

Four Aboriginal participants spoke honestly and easily about their weight management. They were overly concerned about being overweight or underweight. Other patients were not concerned or were not as vocal about it. Anthony and Adam felt emotional and they didn't feel in control of their weight for different reasons. Anthony would like to control his weight but admits to have a problem with going to the gym:

*P: I would like to go back to gym now but what is stopping me is self-consciousness. I have a problem with size. It's very hard for me to go to the gym. I'm just not comfortable with the fat. It is at the back of my head that I am...smaller people would look at me it wouldn't make difference. It's in my head, because I am fat.*

His self-esteem is affected by his being overweight, and he is aware of it, but he is unable to change. Adam doesn't want to change anything, even though he has both legs amputated. He doesn't see any need to change: "I was happy with what I was eating. I wasn't badly overweight. I don't like to experiment". Amy lost some weight and no longer feels accepted by her family.

*P: "My cousin said: How come you're so skinny? Why are you skinny? You are sick. They make me mad...I get mad cause, yeah no one is so skinny".*

Being skinny was connected to being sick and that made her angry. There was a direct connection between being healthy and also being underweight, and also the realization that no one in her cultural group was as skinny. Ann wants to gain weight too, ("like I was I used to be 135 lbs. before"). She feels tired just walking up the stairs but she doesn't have time to see a dietitian ("I am not bothered what is healthy. I don't know. I am busy to go to see a dietitian").

Four out of 17 Aboriginal participants spoke frankly about their weight management. There were various reasons: from being too self-conscious in public, to being too thin and found unacceptable by family members. Actually, two Aboriginal

women felt that they were too skinny and wanted to gain weight. Others did not talk about their weight, most Aboriginal men just mentioned that they walk for exercise.

#### ***4.3.2. Maintaining Weight and Desire for Sweets***

Nine non-Aboriginal participants and four Aboriginal participants explained their moderate concern about weight management and their occasional desire for sweets. Explanations of the four non-Aboriginal participants who raised this theme are presented first, followed by the examples from the three Aboriginal participants' discussions.

It seemed that most patients in this group perceive themselves as successful in managing their weight through their diets and exercise regimens. They spontaneously spoke more and with interest in relation to their diet and weight management. The general tone held by this group is more conservative in reaction to weight management, and they find themselves more stable and balanced in reaction, mentioning both what is easy and what is not, regarding weight management and Diabetes 2 control. They are consistent in mentioning that they "cheat" from time to time by eating something sweet, and they like sweet food but they are trying to avoid it.

Nancy is in the 66+ age category . She lives with husband. She is on medication and a lifestyle program. Nancy is an older woman who is still riding her bike although she is very weak. She lost some weight, she is now happier with the way she is. She has had diabetes for 40 years, exercised regularly.

*P: "I was exercising before but when they put me on the bloody pills I cannot exercise. I use to ride my bicycle in the house little bit. When I was younger I use to play baseball, I use to curl I use to do everything when I was younger. I was active"), and was watching her diet but mentioned:*

*It doesn't bother me too much but you know how sometimes you like having big piece of pie or cake or something you know. That is the only thing but ...you would have your tablespoon and have a bite anyway. I don't go overboard I watch. I 'd like to have chocolate bar you know and I don't. If my husband has one I break, piece like this I think I can have that, can I? Just a little piece this size. yee to have taste. I don't mind if I have to I have to follow it.*

She is watching what she eats:

*I: What food is healthy?*

*P: I don't touch anything with sugar. If I can help it. Since I got this. I don't know I watch, I just If its got too much sugar or I see pies it has sugar on top like crazy its not for me. I don't buy I buy pies for him and I have very thin slice not often.*

Her glucose levels are in control lately with the help of medication:

*I: Do you ever receive any advice on blood glucose monitoring at the Centre? Do you practice it?*

*P: No, I don't know how to do it. He brought it down he is happy. It was 8. Something so and he brought it down to from 13....*

Nicol is in the 66+ age category and obese. She lives with her husband and her children live in Winnipeg. She has had diabetes for a long time without major complications. Nicol was very much in control of her planning and eating habits (“*I just, I go by what dietitian say and buy, and I look and see how much fat it is.*”) After she explained what she eats throughout the day and that she wants to lose weight, but does not feel ready to implement it as indicated:

*P: Basically I think I prepare my food in a healthy way and my problem is that I have pressure control and that I have sweet tooth. Ok. But I think there is some control there. I mean I think about it*

Nina lives with her husband and watches her fat intake, her portion; avoids pasta and bread dishes, potatoes for dinner. She exercises regularly. She also expressed how hard it is to decide what is good to eat when you want to lose weight:

*P: “If you eat a lot of bananas it's good for potassium but there is a lot of starch in it, it is not good for sugar. So what do you do? Banana is fattening too, more fattening than the other fruits. But I have banana mostly every day”.*

She said that it is hard to stay away from certain food certain times of the day.

*P: "Night is a bad time. That's when you are hungry not really hungry but you are watching TV and then when the food come in ...."*

Norma is a woman in her 80s and overweight. She has an old age pension and she said that her income meets her needs. She is dependent on her children to drive her around the city. She lives in a retirement home. She is on insulin treatment.

*I: How long that you are diabetic?*

*P: Forty years. Long time but I was... last year I was in hospital when they put me on insulin. I was on pills before. I am on insulin all time. I was on a lot of medication.*

Norma has a large family, support, exercise, and doesn't worry about anything anymore, but watching her portion and maintaining her weight:

*I: Can you follow all recommendations?*

*P: No. Everything... no.*

On the question does she miss anything I her diet she said:

*P: Yee, sweets, I always use to have candy on the table. Anytime you want candy its there. No more. Sounds very childish. There is some candy now there is no sugar in it. its like jello. Its not very sweet But better then nothing.*

This group was moderately concerned with weight management and was able to stick to the regimen in a balanced way. Although this group consisted of older participants with diabetes they still showed interest in managing exercise and diet to the extent that was possible for them.

Aboriginal participants have similar responses. Five patients in Aboriginal group expressed that they try to maintain their regime and that they are able to manage it pretty good. They are trying to implement something that they learn and sometimes are not successful but generally felt that are trying to maintain their weight and eat as healthy as

possible and/or exercise to maintain their weight. They often monitor their glucose levels regularly.

Tony said that he changed completely his food choices after coming from prison. He said that he was really trying to buy and eat healthy food and to maintain his weight, to be able to feel better. (*“Yee I wanna start eating more fruit and vegetables you know because It’s healthy and so I was never been on that kinda stuff on a regular basis”*).

Arman was not sure about anything asked, and all his answers concerning his diet and preparation of food were *“I guess,” “probably”* and *“my wife knows, she prepares, buys and organizes food”* but when asked about weight control he sounded in control, he proudly said: *“I control my weight with weights. I work out. I exercise a lot. I walk every day”*. He stays away from alcohol, and doesn’t socialize lot. His main reason for not being able to sometimes have better self care came up from being too busy and eating junk food from time to time.

Alice is trying hard to lose weight and to regulate her diabetes and trying to implement what she understands is best for her. It is not always easy but she is actively coping.

#### ***4.3.3. Food as a Temptation***

Twelve Aboriginal and four non-Aboriginal participants explained why it is not easy to manage their weight. Explanations of the four non-Aboriginal participants’ who raised this theme are presented first, following with the examples from the four Aboriginal participants.

Answering a question why he is choosing the food he eats, Harry pointed out that actually: *“Because I am overweight, because I am diabetic primarily most important I try to keep my sugar level under control”*. One of the obstacles to patients for managing their weight was the experience of “food as a temptation” and “the appeal of good food”. They are explained in more detail in order to understand better what possible barriers exist for some patients.

The patients showed more interest in expressing how they would like to lose weight but they cannot. They were able to communicate how desire, temptation and food appeal made barriers against staying with their regimen. They were expressing the need to talk about their weight management more than other participants in the study and in more detail. They talked at length about their inability to stick to the regimen, but at the same time there is a sense that they want and need change but are unable to implement their knowledge due to a love and desire for certain foods.

Norman is trying to eat right and to exercise regularly but it doesn't come easily for him. He wants to lose weight:

*P: “No my wife is trying to lose (weight), I have weight problem I always try to lose weight and with Diabetes it's hard to lose weight because if you are lucky, you don't eat enough then you feel lousy, you need more than you should be eating and then I have this midsection...”*

He loves food and it is a difficult temptation in social occasions if he tries not to take a certain food.

*P: “Always watching it, love to order big piece of chocolate pie. But don't I love those.... that's, on these parties they put all these cheese cake, with cherries and pineapple on top with cream. I make a joke with the hostess: this is especially for diabetics, isn't it? Tell me this is for diabetics (laughter) they say o yea this is for diabetics”*.



He would love to have more advice and support from the Clinic and believes that that would help regulate his Diabetes:

*P: "I have what they say sweet tooth. I like rich food, I enjoy food I like rich pastry I like all these wonderful things that I can't have. That's hardest and loosing weight. Its number one: I wish somebody would tell me: Harry that is what you weight and that's what you weight a year from now and if you follow exactly what I am telling you will achieve that. Because sometimes myself I don't think I can do it because it is too hard. So maybe if I am on more regimen...."*

Similarly to him, Nora would be an example of someone who loves food and has to have it a certain way, but not ready to adhere to any changes easily. She is struggling with her weight and stress levels but doesn't find that she can use the information she gains from the Centre because she has hard time sticking with the recommendations.

*P: And all I remember she wanted me to eat more of this and that than I was, but I wasn't hungry for that is kinda hard when you are not hungry to have more of things. One of the things that I remember was with my bananas. She didn't want me to have it in the morning; she wanted me to have it for lunch time. And I did that for a while, but I wasn't hungry for it ('you know').*

She was listening to her friend's advice who has diabetes to try to find some new information, but she ended up on a similar diet:

*P: She happens to tell me that, it s like we kind of compared the notes and there were different things she told me. 'You are better of having this. O well I've been living out of this, and she would be the one to mention it. And when I saw that person again, I asked about that. I had obtained more information's elsewhere, and then when I figured out that I will obtain it. Unfortunately that's not where I obtained a lot of information. I pulled medical books, but they don't have a lot of information. I was flipping back to Canada food guide, but I didn't have any other source. So my eating habits didn't change a lot, except for the juice that I used to consume. And I probably like it because it is sweet and cold.*

She believes that weight loss would help her whole life and her diabetes management ("If my weight is down everything else will be in order"). She is obese and was diagnosed lately with MS and she knows she should keep her weight down, but her

choices are almost the same as when she was diagnosed. The only change that she made was to stop drinking excessive daily doses of juice. It seems that she understands information, but she is trying to find additional sources (her friend's advice). She loves food and food preparation and she explains it in great detail. It sounds as if food has to be appealing with a lot of colour for her to be able to eat it:

*P: "But most times it is because it is appealing I have to have that color. I have been told like I am trying to tell you I think it is only been in last couple of years I happen to hear a program It might have been body and health or something that if you are choosing foods that are the colourful whether they would been the red the orange and the and the green that you are kind of balancing your vegetables out and that it is good for you in that fashion. I didn't think of it that term for me I need it to be appealing. My mother's food was bland. She might have chicken, and she might have mashed potato and she'll have cream corn well To me for me it is all uninteresting and not appealing to me so even though I like all of these things I just wouldn't have huge desire to be eating it. But if I have my green orange and all that kind of thing to me it is much more appealing to eat and....it turn out it supposedly also better.*

Nathan's example showed general acceptance of disease (he had it for 30 years) with a lot of humour and laughing along with his explanations about weight management and the struggle to reduce the amounts and types of foods he eats. "I can eat everything but I have to watch everything; that is the problem".

He said that fear was a motivating factor for him to stop smoking and to quit some food. He also said that generally it was much harder to quit and reduce food and to change his diet than to quit smoking cold turkey. His attitude is optimistic but he is aware that it's not going to be easy. He is obese and he plans to lose a lot of weight ("At least 100 pounds. yea. But it is hard when you are nearly 70 but I work here I run bingo"). He decreased the portion of food that he ate before.

“I cut out on all meals like I used to make 2 sandwiches and I cut on potatoes. Now I have one. Big one”). There was sadness in his tone when he mentioned: (“I had steak like everybody I cannot have that anymore”).

He cut down on certain foods like bananas and watched his fat intake. He still has his 2% milk, he doesn't like thin milk (“I am trying ..I am having hard time getting the blood count normal like.....make it goal at 7 and sometimes I hit it at 5 which is good but usually it's 10 that's why I try to cut down. Yayaya)

This small group showed a strong attachment to food and were unable to manage their weight and were talking in great detail about it. Here are some examples from Aboriginal patients that talked about food temptations:

Abby said that she is tempted by some food:

*P: Its hard you can't eat certain food./ I try eating at McDonalds sheaf salad. Its good for me that salad. ejej  
Its hard being diabetic./*

One Aboriginal woman mentioned that she loves certain food and that she has to cut on portion:

*I: Do you prepare diet yourself-you said you do? And.....What is hardest recommendation to follow in the diet?*

*P: It's to keep meat portions down. The portions... I find it very hard.*

*I: What about sweets?*

*P: I don't eat that much sweet anymore. That's not too much of a problem.*

*Portion... I like spaghetti. I ate half a plate of spaghetti and I almost fell over the guy says you can have half a cup: what's that???? Hahaha. I still don't have big plates any more. I sell all my plate. I don't have big...I find you have to put it in a cereal dish instead. Just change the dish and it looks like heck of the lot*

Anthony admitted loving fast food:

*I: Was it hard to change?*

*P: Certainly Hahah before I was diabetic was eating more often in restaurants. I love fast food mc junior, Mc Donald I use to take a lot of slurpees a lot of staff I cut out of my life.*

I: Is it hard?

P: *Certainly. I cannot pass by 7 eleven without thinking about slurpee, I use to drink 2,3 a day. so Pretty hard to cut cold turkey but...I notice its is good for me. I can't afford it anyway but I try to avoid fast foods.*

An Aboriginal woman said:

I: *Which food you think is healthy which on is not?*

P: *I know I shouldn't eat pasta, I shouldn't have potatoes. I love potatoes I..ok I ....I eat them as a snack you know. I'll just roast potato in microwave and has that for super 3 times a week. If fit it is not roasted they are fried, baked just because I like potato.*

Aboriginal patients had few food temptations too, but didn't always connect them to weight loss strategies, more mentioning what they would love to eat, and how they are sometimes trying to follow dietary advice. Fast food was mentioned by few participants as desired food, but other food temptations were presented as well.

#### ***4.3.4. Fear of Diabetic complications***

Four Aboriginal participants explained that they have fear of diabetic complications.

Explanations of the four Aboriginal participants' who raised this theme are presented.

Fear of diabetic complications came up in the conversation throughout the interview and was explained through food choices or exercise regimens in great detail. Fear seems to affect their lives in different ways. It seems that they are overwhelmed by circumstances, and that fear of diabetic complications is present to remind them of the disease they have.

Three Aboriginal patients talked about their fears of hypoglycaemia and other complications of diabetes. Two Aboriginal women talked about being unable to change

although there was evidence in the interview that they felt they “should” control it. The apparent level of hardship and their life stories seems to link with their fears of complications of disease although sometimes it looks like diabetes management is not a high priority to them compared to other challenges that they have to face. It may be a sign of being overwhelmed by circumstances. Abby: *“It takes lot from you eh”*.

Two Aboriginal women explained their hard social and personal circumstances as well as mentioning that they were afraid of the complications of diabetes. One Aboriginal man explained how fear motivated him to make better choices and that he is trying to implement his knowledge to the best of his ability, although the cost of food presents a large barrier for him.

Annabelle is a patient that lives in hard social circumstances, a single mother of two boys who is trying to provide for herself and her kids. She is in her mid-forties, works at an unstable job that she wants to change as soon as she can, and doesn’t own a car, which forces her to use the bus for transportation. She is not married and lives with her younger son. She has had Diabetes for a few years and she is on oral diabetic medication and a lifestyle program.

She said she is not eating regularly, not exercising, and drinks alcohol regularly with her friends on weekends. She has a fear of hypoglycaemia and a fear of fainting which she described in great detail:

*P: “That’s when I am not eating or in the middle of the night, my sugar. I wake up in cold sweats and shaky I know my sugar is down. I never passed out or fainted but from my diabetes but I’ve got fear that’s gonna happen one day.... because sometimes in the middle of the night sleeping 4 o’clock in the morning and I wake up and I know I have that cold sweat, I am soaked and drenched, I am shaky and I fell like I am drunk or something. I run down stairs and I check my blood sure enough its 2.1 or o my goodness and I am running to kitchen for juice”.*

She explained that she drinks regularly with her friends every two weeks:

“Because I drink, I drink alcohol and I don’t know I just think I should go back, because world is ugly place it is a lot of disease so yeah”. If she sees the world as an “ugly place with a lot of diseases” she may perceive that fear of disease and the world are an uncontrollable threat to her life. She is under a lot of stress and pressure. She can control some parts of her life, but works at a physical job that makes her very tired. She reports that she is dependant on others’ opinions as to what to eat (e.g. her ex mother in law):

*P: ..yeah I do my ex mother in law, she is everything.... just she is very smart lady and we are still very close. I talk to her every day. She talk to me, She knows my situation and I believe her...She is healthy, she is 82 and she walks her dog every day and she ride her bike and she is very active.*

Her boyfriend used to cook for her:

*P: I used to eat a lot of beans and pita bread and olives and feta I don’t eat anymore as I used to. Because I broke up with him. He is Muslim (laughing) he is from the middle east and I loved his diet It was way better that I use to you know. I loved the way he would prepare food and stuff like that.*

*I: You broke up?*

*P: We are back together but I am stuck in my ..and he doesn’t cook as he used to. We used to eat a lot of rice, a lot of beans, a lot of feta, pita as I said. Stuff like that, lentils. But we don’t eat that any more.*

*....with my diabetes if I get hungry I get so hungry that I get so nauseous. I am not even greedy type of person I was never like that but as soon I know I am hungry I quickly go to, just feeling that I am going to throw up. It comes so strong. I’ll eat a lot of rice crackers I eat those every day. (laughing)*

*I: Do you ever receive any advice on blood glucose monitoring at the Centre? Do you practice it? Aah no not really when I was first diagnosed I was told monitoring and stuff, how to check my blood and stuff and that was one time think. That was basically it.*

She admits that she doesn’t like to monitor her blood levels regularly because it is time consuming and irritates her. There is an interesting link between her actually having better control over her diabetes and her resistance to follow routine.

*I: Do you practice it?*

*P: At first I did because I was curious and then I got tired of it because it was always high my sugar was always high and I'll get mad I didn't want to know so then for about 3 months I wouldn't check and when I would check it would be 29, 28, 22, it was never normal. My doctor was really trying to get my sugars stable. And just recently about 7, 8 months we got it under control kind of it I sometimes high it's not as high as it use to be but sometimes 17, 15 which is still high. Greater separation is required between interviewers and participants comments.*

*I: Are you on tablets?*

*P: O yeah. I don't even know what is better higher or lower I don't check like I use to. Even now when I know that it is under control at first I was excited about it, every time I check it it was oo its 8 or its 7. I you know what I mean these are the numbers that you want to be. I am happy about that but I get bored about and I don't even know now what my sugar levels are. It is annoying aa its time consuming it It's annoying to me I don't like it.*

Her perception of her weight is different than her actual BMI:

*I: Are you planning to change the amount of any foods you eat? – Which ones? – Why?*

*P: No I don't think so. I don't mind my weight. I feel that I am a little too skinny I can't help that. I always was skinny I don't know.*

*I: You are o.k.?*

*P: yeah.*

When the kids are with their dad she doesn't cook at all. This is what she said:

*P: I basically eat a sandwich or bagel. "I don't turn my stove for 2 months (laughing)". She has a completely different method when it comes to treating her children regarding their diet and exercise. "If he is at home with me I'll try to cook a meal every day. And there are times that I am too tired and then I'll order. I'll take them to Mc.Donald's or something like that".*

She distinguished a few times during the interview that she treats them better than herself and feels guilty that she drinks because of her children and not because of herself.

It sounds as if there is great conflict in her life (hard job meant to support and provide for her family, depends on others for her food choices) and her underlying fear (

“ world is ugly place it is a lot of disease”). She is aware of the need for change and she may want to be the one to execute it. When asked about social support she said:

*P: “I don’t even think I need support that way. I am not just like that. I don’t need anybody. I wouldn’t need anything from anybody if I need change my lifestyle that would be my option”.*

Abbie is another example of an Aboriginal woman, who expressed fear of hypoglycaemia. She was 47 years old at the time of interview living alone, and had three boys (one son lives in the city). She uses the bus for transportation and lives on a disability allowance. Her mother lives in Winnipeg and she is on a lifestyle program. She didn’t mention how long she has had Diabetes or the extent of her complications in the past. Abby’s food choices were based on fear when her brother died from kidney complications.

*P: “Because all my family is Diabetic. Two of my brothers are on dialysis know. And my brother died from kidney complications. Then I get scared ejj. I better cut down as much as I could. Yee”*

That was her motivation to make some changes. Generally, she still lives day by day. Her life is all about trying to cope on her own, as best she can. She lives in poverty, walks to her boyfriend every day, eats with him, and usually eats when hungry. Both her sons are in jail and she doesn’t care about herself anymore and mentioned that she is severely depressed. It seems that fear serves to wake her up from time to time, but her overall depression and circumstances are pulling her in the direction of self- neglect.

She acknowledged that when she made some small changes in her lifestyle it also had an impact on her control over Diabetes.

*I: What information you hear from this Centre?*

*P: O jee all the information. Control diet and this and that.*

*I: How you use it?*



*P: Hahah. If I can... I grab a bar which I am not suppose to do but I still do it you know what I mean. From time to time. Not always. I try my best. Since I start walking my sugar s been 6,5 because I exercise ejj. You know I feel much better when I am walking.*

She mentioned how difficult it is to follow recommendations:

*P: What I buy because I don't buy chocolate bars I don't buy this and that but I buy meat, potato and canned vegetables. You know its gotta be you to control yourself jee but it is hard ejj.*

Anthony is an Aboriginal man between 36-45 years old, unmarried, has a brother and sister in the city and lives with a roommate. It's been a few years since he was diagnosed with diabetes. He doesn't have major complications but he was admitted to a hospital in an acute state, close to a diabetic coma. He has high BMI. Anthony is a good example of how fear can motivate patients to make different lifestyle choices and to try to control food choices. His prior lifestyle was based on eating a lot of junk food and regularly eating in fast food restaurants. He mentioned that he never learned at home the importance of a healthy diet. His eating habits were to eat once a day, accompanied by drinking pepsi and slurpies. His fear was an alarm that motivated him to make different food choices. Anthony said:

*P: "I almost died when I got to a hospital. I was so sick; I was so close to a coma. When I got to the hospital I couldn't tell my name, I was delirious, it was pretty bad. When I got better I realized how bad it was. After that I said its time to make different choices. My body is not going to bounce back as it used to".*

He is aware that he needs to change his diet, and he explained that his biggest barrier is lack of money to provide better quality food.

*I: Where do you get information on where to buy food?*

*P: You know a lot of stuff I prescribe that think on the Internet (what is it called?), it tells you the worst foods a lot of stuff learn from that, ideas and stuff. Tell you about diabetes what you should or shouldn't eat. Unfortunately I cannot afford it. I didn't learn much from my family. We are all meat and potato family most of the time growing up. I came to the city 1970. I was 19. I learned from school, friends,*

*buying books. Years ago I talk to dietician I took a lot information from that. Look at Canada Food Guide.*

He feels that he needs to lose weight, but he doesn't feel comfortable going to the gym. It is still blocking him from exercising regularly. He is conscious of his weight which doesn't allow him to exercise although he would love to lose weight.

*I: Do you exercise?*

*P: Not as much as I should. I cycle, I go for walks every day, but I used to go to gym seven days a week. I would like to go back to gym now but what is stopping me it's self-consciousness. I have problem with the size. It is very hard for me to go into to gym. I do go to gym maybe couple times.....*

He is an example of a young Aboriginal man trying to adapt to his diabetes and to make better choices. He has difficulties in following the regimen, and he knows that he should lose some weight. He is trying to be creative with his friends to make meals at home so he doesn't go out and eat junk food.

He uses information from the Internet to be able to understand which diet would be good for him and how to implement it. He linked his dietary habits with his ability to manage his diabetes.

*I: Do you receive advice on glucose monitoring? No. I usually monitor my glucose level at home; occasionally bring the glucometer to her. I am actually quite surprised I managed to maintain my sugar level pretty normal between 5 and 7. I manage to maintain it. Well for the first month it was high, but for the past 4,5 months I managed to keep it. It was a couple of times when it was higher abut a month I wasn't eating very well.*

According to Anthony fear was a motivator to make changes, but other factors such low affordability of food are obviously important factors in his decision making process in regarding food choices.

*P: "Well, I am not even sure what the diabetic diet is, (laughter) but I know that they told me to try to eat normal, in normal times of the day."*

Three out of 17 Aboriginal participants indicated that they experienced a fear of diabetic complications and connected it to their lifestyle choices in different ways. Fear could have had a paralyzing effect at some level in the case of Annabelle and Abby, and it was mentioned as a motivating factor in Antony's situation.

An emotional reaction seems to have an important role in connecting some patients with their lifestyle choices. Other patients did not explicitly mention fear as a factor in their decision making process. Adnan is in the 66+ age group. He lives alone. He is on oral diabetic medication and a lifestyle program.

Adnan was very sure of himself; feeling efficient in controlling his food choices, and controlling his weight. When it came to the topic of the possible use of insulin injections he seemed extremely disturbed stating that he would never use them because his wife was a diabetic for many years and he saw her suffering through the insulin shots.

*P: Like me I wont take a needle for many years my wife.... but the pills seem doing good why should I take needle? You wouldn't if you have to? No I wouldn't take needle. I saw her, 20 years it's enough. Watching somebody poking themselves that's....(he didn't finish sentence)*

He made the link between his diabetes control and his lifestyle choices:

*I: Is it hard to follow?*

*P:.....No. My sugar levels I test it every day it's perfect being diabetic. This weekend it jumped I don't know why but otherwise...*

*I: So it s stable?*

*P: It's around 6,7 you know.*

*I: Do you monitor it?*

*P: Twice a day. I got that .. you can't go wrong. I put time and day. I walk 2 miles a day with dog.*

*I: Every day?*

*P: Every day yee. In the morning and if its not hot, even around the block where I live*

His regular monitoring the blood and watching what he eat that he is “perfect being diabetic ” may lead to the possible conclusion that his immense control could be a direct by-product of his fear of having to take insulin.

Two of non-Aboriginal patients brought up that they have fears from diabetic complications too. One participant mentioned: “Yea I *mean I am and wasn’t that consistent. I avoided some stuff that are dangerous diabetes scared the hell out of me*”.

Nathan admits to having *fear* of hypoglycemia and other serious complications:

*P: “I got polish through 2 or 3 pork chops no problem but then I pay for it I have to pay for that meal I take that blood check...then you see 22, 24..... yeah, that is scary too. If you have hyperglycemia not as bad as.....not as bad as going down low. If you going 3,4 you going shaky and...stuff like that...but up to now I’ve been to the needle but you are still at risk you are at risk for heart.... kidneys shut down or.... ”).*

Other patients didn’t talk about fear of hypoglycemia.

#### **4.3.5. Depression**

Two participants explained how they feel depressed. Explanations of the two Aboriginal participants’ who raised this theme are presented. One of these interviews was very emotional and disturbing. The woman’s story was not typical, but rather unique. This story was chosen to show the dramatic effect of poverty and hard personal circumstances in the life of one Aboriginal woman, as well as her struggle to control her diabetes.

Abby explained how her lifestyle choices are exaggerated by her current family situation. ” She said: “*When you are alone you cannot cook a meal*”. She depends on her boyfriend to cook for her and she is not close to her family and doesn’t have any other

support. Her whole family is diabetic and they have a hard time coping with diabetes too.

*"My mom might be there for me, but you never tell me what to do or to eat (laughter)".*

She was very emotional when asked what is keeping her from following the recommendations she got from the Centre. She immediately answered:

*P: "My kids, I don't want to talk about them, .....and that I get so depressed. I just even want to kill myself, sometimes heh. Not always".*

*I got depression feeling. I have problems with my sons. ....eh and everything is like....on top of that my friend drowned. It takes a lot out of you eh. I have this I'll have that. I don't care about myself anymore. But that attitude eh. My family is Christians. They are all Christians they all believe in non-drinking not smoking and everything. My mom always talked to me, my mom always tells me: You shouldn't go down that path Abby.*

*And I am not going nowhere. I am here I am not feeling sorry for myself, you now what I mean these things happen.*

She was implying that she drinks but she avoided answering directly. Although through her story about her mother, the drinking dynamic can be understood by the fact that her mother disapproves of it. She directly connected her eating habits with her depression and desperation. *"I grab this. I'll have this I'll have that. I don't care about myself anymore"*, she said. She is aware that she should control her eating, but she said *"it is day to day eating"*. It seemed that her life desperation, depression and addiction are leading her to self-neglect.

One Aboriginal man mentioned that he is depressed. If depression is the case, some patients may feel that they have no appetite or will have an increased appetite. He lost both of his legs due to diabetes. He feels that food is an antidote for feeling down and depressed *"I got this depression I eat more and it becomes a never ending cycle."* He doesn't work and he said that it was difficult for him to accept that. ". He doesn't have a social life and copes on his own.

*I: Have you recently change the amount of food that you eat?*

*P: Probably eating more no, quantities. Depression and after working so many years at one job I lost it I suddenly feel depressed.*

*I: Do you see anybody for depression? No, not really. Try to handle it. Food become substitute. I realize it ; when you fee. l down you eat more? Yeah that when I am feeling down. I need more activity.*

*I: Do you exercise: Physio.*

*I: You have amputated both legs?*

*P: One was 2 years ago and one about 15 months ago. Because of diabetes. They took one because it was badly ulcered. They try to save it but they couldn't. I lost both of them. I keep that I'll back at work but ...Maybe I am just dreaming. .*

He feels that his diabetes was under control, but due to unexpected nature of disease itself he developed complications, although he was doing everything he knew to prevent it:

*I: Is it hard to get or more expensive?*

*P: It's probably more expensive but it's not because I can't afford it but it is matter of personal choice that I particularly follow it. Even I lost my legs not because my sugar was out of order, because what I was eating (because my sugars were between 5 and 6). My levels gone up I develop all kind of problems with my legs, I was going to foot clinic every month doing everything that I thought it's doing good for me. It didn't.*

He feels that he is not ready to change his diet, neither to lose some weight:

*I: Do you use recommendation for diabetic diet?*

*P: No. I went to diabetic classes at the hospital; I was in rehab after amputation. I took one of these diabetic education courses just to fill in the time (Laughter)*

*I: Did it help?P: No.*

*I: Did you want to change?P:No .*

*I: Why was that?*

*P: I was happy what I was eating. I wasn't too badly overweight. I was working but aa... But sometimes I feel like ..I put on about 30 pounds. My physio keep saying" lose weight" and I keep saying" I know, I know".*

#### 4.3.6. Fatigue and Tiredness

Participants didn't generally talk about physical aspect of how they felt with diabetes but four participants (two Aboriginal and two non Aboriginal) explained how their feelings of fatigue or tiredness may influenced their lifestyle choices or connecting it to their glucose levels. Explanations of the two non- Aboriginal participants' followed with the examples of two Aboriginal participants who raised this theme are presented. This was explained in different parts of the interview and was in different contexts to patients. It seemed that it was mentioned briefly but is connected as a reason for their choices.

Norman is example of non Aboriginal man in his fifties that mentioned few times during the interview that he felt physical weakness. When asked about snacking habits he answered:

*P: What happens is that after breakfast I go and generally 4- 5 times a week go for a workout at Wellness Institute. When I go to Wellness Institute, if I don't go enough for breakfast after workout I barely have energy because my sugar is dropping low to even get dressed. On time I set there I said to someone near me I was like.. get me some chocolate bar.. or.. some juice I am going to pass.. you know. I generally try to eat my breakfast so that doesn't happen. When I take sugar count before the snack its generally about 3.4, 3.2 then I have snack generally fruit, an apple or an orange. If I take my glucose monitor and I see that I am really low... I'll have a piece of bread... Always dark bread.*

When he talked about his exercise regime he said:

*I: You exercise. How often?*

*P: 5 to 6 times a week.*

*I: Do you walk?*

*P: I find hard walking because I suffer from leg pain because of the diabetes. What are they call it? I forgot. I walk. I sit down... I use machines for upper body exercise and sometimes ...once in every week I take water aerobic. I feel the*

*exercise, it lowers sugar. I feel exhausted from it. I don't feel terrific. I feel totally exhausted.*

Harry expressed that he felt physical weakness while exercising and connected it to his diabetes. He mentioned that he is depressed too:

*I: Is it changing your social life?*

*P: Depression and diabetes sometimes I feel very weak..... with depression I don't feel like mixing with other people. sooooo. I keep away from extremely active social life. Is that answering the question? I don't know...*

Nora mentioned "I often feel tired" (recently diagnosed with MS, too), and she made connection with her tiredness and her stress levels to her glucose levels in the blood.

*I: What about a glucose monitoring?*

*P:..... I wasn't told that I needed to do monitoring several times. I was doing once a week, but I maybe doing it twice a week when I first started. There were pretty much the same. There were not huge variables. My levels were probably higher in the evening than during the day. If I was working then my levels were lower, but if I wasn't working my levels had tendencies to elevate. But it made the difference what was going in my life. If I were super tired, going through stressful times, financial difficulties that kind of thing that kind of thing would reflect in my levels. My body was reacting although; my body was saying there are things going on, you know.*

Amy is in the 46 –55 age group. She lives alone doesn't own a car and works part time. She is on medication and lifestyle regime. She didn't mention how long she has diabetes. Amy said that she feels tired just walking up the stairs

*I: Exercise? I don't have time.*

*P: My exercise is going up the stairs. I feel tired going upstairs.*

When asked to explain further she gave quick answer :*"But I feel tired all the time. I lost weight because of that", and she become silent.*

She feels extremely tired all the time but monitoring her blood sugar levels is hard, she is too busy to do it. Her overall tone was low and she talked slowly and in very low voice answering in short answers when talking about her food choices, but commented in the middle of the interview that she doesn't like that she is diabetic and she didn't like to talk about that with her family members.



*P: My aunt is diabetic, my brothers are diabetic. But they don't talk about it because they don't like it as much. I don't like it at all. I hate being like this. I don't talk about that. (Feeling uncomfortable coughing) They talk amongst each other. When they talk I just leave.*

*I: You don't talk about it? No.*

Amra belongs to 56-65 age group. She lives alone and she lives on welfare. She said that her income doesn't meet her needs. She is on medication and lifestyle program.

Amra mentioned at the end of the interview, after talking about how her diabetes influenced her social life, that: "I feel tired walking to the store, then I eat junk food".

She lives alone and prepares food for herself. She said she is trying to implement information that she gets from the centre and she is trying to avoid eating certain foods that she ate before. She doesn't complain about it, but there is a certain monotone answering certain questions about her lifestyle.

*I: What is the hardest thing to follow?*

*P: No, these are my chips, you know. I use to eat that. yee I miss that food. I used to have chips.*

Only topics such as social life, diabetes, and fatigue which were brought up spontaneously, resulted in a reaction and seemed to hold meaning with her. It sounds as if her choices may be deeply affected by her physical health (fatigue) and she may perceive that as her barrier to better choices. Her social life is affected by it too. She might feel angry with the fact that she cannot eat what she wants and that she needs to gain weight in order to be like everybody else. That puts her in a difficult situation in which she wishes to "normalize", to be like everybody else in her social setting and to control her diabetes regardless her physical fatigue. She found connection between her food choice and her sugar levels.

*I: Do you ever receive any advice on blood glucose monitoring at the Centre?  
Do you practice it?*

*P: Yee I check it. If you eat a little bit of fat food it sugar go up.*

*I: What do you do?*

*P: Then I walk.*

It seems that that she is suffering from disease symptoms but still avoiding addressing her problem. She doesn't have time to see a dietitian ("I am not bothered what is healthy. I don't know. I am busy to go to see a dietitian").

While talking about weight management and exercise regime, Norman and Nora linked tiredness and fatigue as a result of diabetes, directly. For Amra and Amy however, it was mentioned indirectly. They mentioned fatigue and tiredness briefly but in connection to their lifestyle choices ("I feel tired walking to the store, then I eat junk food"). Amra and Amy shared their life stories but avoided talking about the symptoms and effects of diabetes in any great length. By telling these stories they gave subtle signs about the link between their diabetes symptoms and their day to day lifestyle choices. Even if the approach was indirect, the reason for it could be a culturally different form of expression, hard life circumstances, or it may be that both play a role in how participants expressed their views. All four patients have other medical problems that they mentioned and could also be the reason for their fatigue and tiredness.

#### ***4.3.7. Discussion of "Perceived Coping and Control With Type 2 Diabetes"***

A major objective of the study was to document the reasons why some patients with type 2 diabetes feel that they are in control of their Diabetes, and why others do not. Some patients showed more concern about their weight management and disease control. It seemed that they felt the most control over their disease through weight management.

Four patients mentioned how hard it is to manage their diet and exercise regimen and the reasons for it.

Some patients said strongly believe that they can control their weight indicating that if they make an attempt they will be successful in managing their disease. The majority believe that when they decide to make a change that it will be possible to drop the pounds through diet or exercise, or both in conjunction. There is an overall impression that they are actively involved in their self-care, weight and exercise control. They indicated that they were confident in their general knowledge and they said they implemented what they thought was good for them. Most participants that fell into this group were non-Aboriginal.

Some patients did not express such confidence that they were in control and being able to manage their weight, but generally indicated that they were following the nutritional and lifestyle guidelines given by the Centre. Their reactions were more conservative and gave the impression that they were trying to implement a diet or an exercise but were not as vocal about it, though neither did they express that it was difficult to manage Diabetes.

The Aboriginal patients in the group expressed their thoughts and feelings regarding their attempts to maintain their regimen. They said they were trying to apply some of the things that they have learned but were not always successful. Generally they said they were trying to maintain their weight, eat as healthy as possible and/or exercise to maintain their weight. Most of them monitor their blood glucose regularly. Only one Aboriginal man who was concerned about being overweight talked about having hard time managing his weight.

Three non-Aboriginal patients talked about how hard it was to manage their weight. They actively made an effort but were openly sharing their love for food and their struggle to eat and exercise regularly. Two men to expressed feelings of temptation and desire towards certain “forbidden” foods and one woman talked about how important it is for food to be appealing and satisfying to her tastes.

Fear of type 2 diabetes complications was prominent in a few patients, it seemed as if it served to “wake them up” from time to time and remind them that they have the disease. They seem to have a hard time with the diet regimen and their life circumstances appear overwhelming for them. Their feelings were expressed in different parts of the interview and usually came up spontaneously. Fear and depression came up as the most prominent emotions and were expressed with the most meaning and at greatest length. The greatest fears came from having short term and long term complications such as hypoglycemia or kidney dialysis. It is not clear whether this aspect is in relation to their life circumstances, to underlying co morbidity, unmanaged diabetes, or from witnessing family members suffering the same complications. It may be that all these factors are in play.

Participants were more focused on poverty, social and personal hardships (ranging from living alone and not being able to buy certain diet foods to not being able to make a contribution due to unemployment). Three participants (Aboriginal women) expressed their desperation in relation to the circumstances of their lives as well as a feeling of total powerlessness and self-neglect. Most patients in this group were not able to monitor their glucose levels daily and they were having problems maintaining their dietary regimen.

It seemed that in discussing difficulties in diabetes management, Aboriginal participants spoke more about their emotional and mental health, affordability of food and different life problems. They talked about depression, fear of diabetic complications and other realted stories more and in greater length then non Aborigianl patiens. It seemed that life burdens were strongly influencing Aboriginal participant's perceptions on their coping with diabetes. Non-Aboriginal participants talked about their struggle with weight management more and with greater interest.

Weight management is an important dietary and therapeutic goal in obese patients with type 2 diabetes (Meltzer et al., 1998). This indicates that most patients are aware of the importance of weight management and their condition. They may have considerable knowledge about it and said they mostly making an attempt to implement it, with varied success. Unfortunately, no dietary method has been demonstrated to be effective in achieving and maintaining weight loss (Cummings, Parham, & Strain, 2002).

In the report "The dietary treatment of Diabetes Mellitus: Dietary recommendations for type 2 diabetes claim to be similar to those for the general population, table sugar and foods containing sugar do not need to be restricted, and weight loss should be established (Bantle JP, 1998). "Patients should not be stigmatized for failing to lose weight, and weight cycling should be discouraged." (Nutall, Chasuk, 1998).

The desire for sweets and food appeal is found to be important in a few patients, a finding which is consistent with previous studies. Food cravings are extremely common. Prospective and experimental research shows an obvious association. "Dieting or restrained eating generally increases the likelihood of food craving while fasting makes

craving, like hunger, diminish. Attempted restriction or deprivation of a particular food is associated with an increase in craving for the unavailable food. This relationship suggests a variety of underlying cognitive, conditioning, and emotional processes, of which ironic cognitive processes, conditioned cue reactivity and dysphoric mood are prominent.” (Hill, 2003).

#### **4.4. Diet Regime and Exercise**

An exercise regime and diet are crucial parts of type 2 diabetes management. It is important to recognize the perspectives of patients on their lifestyle choices, and their reasons for behaviour to be able to help them tailor their lifestyle program to their needs. Many different reasons affect a patient’s daily food and exercise choices that may promote or hinder their success in maintaining a healthy lifestyle. It is important to know the barriers that patients encounter in their everyday management, their thoughts and feelings and to share in their successes. Every patient has a unique perspective but there may be some similar concepts that most patients hold which can help us to better understand their emotions, as well as how their learned behaviours may be difficult for them to change to the ones suggested for them.

The food choice map was used in this study as an integrated semi-structured interview to be able to more naturally engage with type 2 diabetes patients regarding their food choices, and to be able to focus their interest on the map, making them interactive and interested in the process. This method helped patients to relax and to participate freely and with great interest. Another advantage to this instrument is that patients

uncovered their stories through very light conversation and the researcher was able to capture the deeper underlying meanings behind their reasons for certain behaviour.

However, exercise was not discussed to any great extent, which may be related to the method used to prompt discussion or may be related to the participants' interests. Consequently, the following discussion focuses on participants' perception of their diet, although exercise will be mentioned as it is raised.

#### **4.5. Objective 2: Perception of Diet Regime and Exercise**

Participants in this study talked openly about their diet regime. It came up spontaneously in conversation about food choices through making the Food Choice Map during interview process. Many patients explained that they have a hard time focusing on regular meal planning and that they prefer eating naturally (without much planning) or they have strong food preferences that make it difficult for them to stick to the recommended diet regime. During the interviews many patients reacted negatively when the interviewer used the word "diet" which prompted an exploration of the topic of "resistance to diet". Other topics discussed include "trust in health care professionals", "family cooking traditions", "unfocussed eating" and "food preferences" and "just eating normally".

##### ***4.5.1. Resistance to the Diet***

Eleven out of the 21 non-Aboriginal participants and two out of 18 Aboriginal participants mentioned in conversation that they didn't feel as if they were on a diet. If the interviewer mentioned in conversation "diabetic diet" or "diet" they responded by

commenting that they are not on a diet. Almost all of them said they had a strong sense of control and indicated that they were trying to make better choices with food and exercise, but there was an overall feeling that they were not on a special diet, and that this is the part that they can control. It seemed that their sense of control stemmed from being able to choose what they want to eat and when.

That control was expressed in different ways, both directly and indirectly. Some patients were direct (“eat what I feel like eating”, or “*nobody is gonna tell me what to eat and what not*”, “*if you tell me I do opposite*” and some may be hidden under “*I know what’s good for me*”, or reacting to irrelevant label “*I don’t consider it diet*” and “*I eat three times a day and at “normal” times*”. It is not always clear if just label of diabetic diet provoked patient to react (their dietitian may encourage them to follow healthy eating patterns) nevertheless they gave some interesting responses.

Nadia was only angry when explaining: “*When somebody mentions diet I am ready to hit the sky. As long as I don’t hear diet everything is fine, when I hear diet I don’t know. As long that I don’t hear diet everything is fine*”.

Nathan also expressed a strong need for control over his food choices “*I am going to be honest, there is nobody who is gonna tell me what to eat and what not. You smarten up pretty fast*”. He said that it was hard to quit certain food as he quit cigarettes cold turkey: “*The food was my god you know. I could live without anything but not without food*”.

His example shows that he is trying to implement some of the recommendations because he wants to reduce his weight and there is some evidence that he fears hypoglycemia but his last statement : “*I am going to be honest, there is nobody who is*



*gonna tell me what to eat and what not*", suggests his resistance to authority is as strong as his motivation to do something about changing his eating habits and may be causing conflicting emotions. It may be making it more difficult for him to decide what he wants to do.

He has eggs in the fridge that he didn't eat because he heard that the yolk is not good for cholesterol. He wants to implement the information that he hears, by not eating the eggs, but he still doesn't want to let go of the eggs. That may be a symbolic illustration of the difficulty in implementing something that is hard to believe. It seems that resistance to make a change and the need to implement certain health information are conflicting and represent his challenge to overcome it.

#### ***4.5.2. Trust in Health Care Professionals***

Norbert is an example of someone who doesn't trust doctors. He talked about the doctor that he met when he had skin complications due to diabetes. He said: "*He was more impress to be a doctor than to help you*" and "*If you don't trust in doctor there is no sense going there*". In his case it sounds as if he has no trust towards health care workers. He mentioned: "*But I am procrastinator, if you tell me I do opposite or not do it at all*". When asked whether he sticks to his recommended diet he laughingly mentions: "I use it, I don't mind it; but just sometimes I go by my taste. I eat whatever I like".

Alec reads books about the diabetic lifestyle and trusts them more than health care providers. He said that he eats what he finds to be convenient for him (less cooking and easy to prepare food) and tries to pay attention to his body whenever possible because

that book helps him to better understand how Diabetics feel and what the best way is to listen to your own body and then respond to it.

#### ***4.5.3. Family Traditions: Cooking***

Two older non Aboriginal participants found that for them it was the most important thing to cook as their mothers cooked. When one was asked where she got her information on what is healthy to eat, she said: *"I know what's good for me, I know I am eating what my mother used to cook you know"*. Her mother was from Europe and she learned to cook from her and because they lived through the depression her spending habits stayed the same. She cut her portions and lost some weight but is unable to exercise as much as she did when she was younger. She did indicate she was more careful with the fruits and pies.

*P: When I go to the store I'll buy these potatoes dumplings my mother used to make, cabbage rolls she told me how and I make roast once in two weeks or something and we have roast for..I slice up potatoes and make a meal for my husband you know. I don't open too many cans except for vegetables you know. But I buy potatoes, onions by the bag. I buy carrots.*

Nadia was only angry when explaining: *"When somebody mentions diet I am ready to hit the sky. As long as I don't hear diet everything is fine, when I hear diet I don't know. As long that I don't hear diet everything is fine"*. Her whole family has diabetes (her mother and her two sons). She grew up in a very poor family that has a lot of children. She prepares food that she is familiar with and learned from her mother. She doesn't want to learn anything new in order to protect herself from new recommendations and implementation techniques. She combines foods the way she understands them.

#### 4.5.4. Just eating “normally”

Aboriginal participants didn't show as much resistance to the mentioning of diet.

Two Aboriginal patients commented that they were not on any diet, although in terms more expressive of the idea of “normalcy” than opposition to the label:

*P: Well, I am not even sure what the diabetic diet is, (laughter) but I know that they told me to try to eat normal, in normal times of the day. Normally I am not a morning eater; normally I wouldn't eat till midday.*

His repeated use of the word “normal” implicitly contrasts his idea of normal with that of his health care providers' and perhaps implied a desire for more knowledge. He continued, stating that his only consultation was at the hospital and he never received advice from the centre. He is using Internet as his guide and explained that his family was meat and potato eaters and that he never learned importance of regular meal planning and what a healthy diet is.

Allan is example of someone serious and persistent in trying to maintain his weight and to change his eating habits after coming from jail where he was diagnosed with diabetes.

*I: What is hardest recommendation to follow?*  
*It is not really hard to follow. I guess the bottom line is when I was diagnosed with diabetes I was in jail. It is not good place to try to deal with something like that. So when I got up in November I have to deal with it.*

He follows recommendation from the Centre:

*I: What information do you use?*  
*P: I come here and see (dietitian) talk about diet and what should implement and what not. I get a lot of information from her.*

*I: Can you follow it?*  
*P: Definitely. When I first come in here my food intake was a big problem so I first talk to (dietitian) try to cut down that so I follow that. Yee.*

When he talked about what changes he made in his daily dietary regime he mentioned he raised his voice: “I don't consider it diet ” “Healthy eating? Aa yeea...

He but didn't give more details about it.

These participant may both good examples not so much of resisting the concept of diet, but more of reacting to a perhaps irrelevant label. The first participant said that he wasn't even sure what the diabetic diet was; that "they" told him to "eat normally." His commentary is a reaction to the word, "normal," contrasting his normal with what he presumes is the unknown normal he is reaching for and is trying to learn more about.. The second participant, Allan, is want to follow the dietitian's advice, says he "definitely" follows it, but is not on a diet. He seems to react to the label, "diet" rather than the dietary advice he's trying to follow.

#### ***4.5.5. Unfocused Eating and Food Preferences***

This category is about spontaneous decision-making. Patients frequently spoke about not being able to have a planned meal or deciding to eat something spontaneously based on what they have in their fridge. These patients reported they often skipped meals and ate randomly whatever is available and whenever they feel like eating. Four Aboriginal and no non-Aboriginal participants made comments that fit in this category.

Annabelle said the hardest recommendation to follow was eating a three-course meal because she usually grabs whatever is on her way. She doesn't have breakfast or even lunch. She said that it is hard for her to follow diet regime. She eats whatever is available without planning.

Abby reported eating "*day-to-day*", consistent with other patients that used similar language in explaining how they eat throughout the day.

*P: ...I don't eat till hungry, when my sugar goes down I don't eat till then.*

*...I just eat when I am hungry. I am diabetic but I grab whatever I can grab and eat.*

*...We don't eat any breakfast. You eat this and that. It's easy.*

*....If I can, I grab a bar which I am not suppose to do, but still do it you know what I mean.*

It seems that there is an awareness about having diabetes and understanding the importance of regular eating habits but there are reasons, from possible being more convenient (easy) to respond only when hungry, or when sugar goes down.

Anthony explained a barrier to following his regime is:

*P: "I am not a big morning eater. The hardest thing for me is to eating few times a day" .....I just start doing this when I got sick.*

*It's just I was never, you know. My eating tends to be later through the day.*

*I think one of the reasons I spend working day shift so I wouldn't eat later at day.*

*It's forcing myself to have a breakfast. It's little tough because I am not used to eat first thing in the morning. I am not hungry you know.*

Anthony has problem focusing on routine eating habits, and frequent meals.

*P: ...Breakfast is important. Well because of the diabetes now, they were pushing me in the hospital about eating. It's hard to maintain it. They were pushing me 4-5 times a day. I try to eat 4 times a day.*

Anastasia said that she felt better when she gave up drinking and smoking and that she is able to take some control over her disease.

*P: I diet help me and because I quit drinking. And quit smoking.*

*I: Few years ago?*

*P: No since December. 8 month now. That helped me a lot.*

*I: How much did you drink?*

*P: O, I don't know (laughter)I feel better when I don't smoke and drink. And I want to stay there. I was very sick. I wouldn't take my pills when I drink.*

*I: Now you take it regularly?*

*P: Yee, every day.*

Anna mentioned "You can't always eat.....Because sometimes I forget or you just do this and that. It bothers me...". Ann and Anthony expressed how it is hard for them to

control their eating habits, although both try hard to eat right. Ann wants to feel better and to make better choices, but it is not always easy:

*P: "I do. Some days I can go along every day and pay attention other days I eat what I want to eat. Before I was always eating what I wanted to eat I was getting sick. I know what my body tells me so I try to listen to it more".  
I would just sort of ...be nibbling. And what I would be nibbling on toast, peanut butter. And I wouldn't be worrying about lunches.*

Most patients in the non-Aboriginal group indicated more preference towards certain foods and were generally more focused on what they ate. They talked more about their food choices. They focused more attention on which food they choose to eat. They mentioned often which foods they like or they don't like to eat for various reasons. Their choices are mostly dependant on a food that their body desires. It may be food that they are used to eating as children or food they have preference for.

Most patients in non-Aboriginal group have strong food preferences toward and were particular about which foods they chose and why and were interested in mentioning their favourite foods. Very often they would say "my noodles" or "my rice" or "I have to have my fish", indicating possession and particular identification with some foods. They indicated that they have regular eating habits and tried to stick to their own or a recommended routine.

#### ***4.5.6. Discussion of Perception of Diet Regime and Exercise***

The second objective of this study was to document the reasoning behind the lifestyle choices, including food choices, physical activity and other social behaviours. Three Aboriginal women explained that they eat when they get hungry, when their sugar goes down or when they are weak or fatigued. They don't plan their meals ahead of time;

they say they eat whatever they have in the fridge. The patients often spoke of not being able to have an intended meal or that they would eat spontaneously based on what they had in their fridge. They often skip meals and eat randomly (whatever might be available).

For two women it is hard to eat alone, and for another other two it is hard to cook. Only one woman cooks, and that is due to the fact that she lives with her father and he helps her prepare breakfast and lunch during the week. Over the weekends she eats whatever is available in the fridge and is not able to maintain control over her eating. Two women have somebody to cook for them and one cooks for her children when they are at home, but not when she is alone. Two reported drinking problems and one explained that she has regrets as a result. Four reported that they quit drinking with one explaining in detail how she lost friends when she quit drinking.

Aboriginal men reported that they were feeling more in control of their eating habits. One explained how hard it is for him to maintain a regular routine with breakfast every day, but he is actively trying. One, who was dependent on his wife to decide on the food he ate, said that it is hard due to a busy lifestyle, but he is implementing most of lifestyle recommendations. He made the connection to not drinking. He quit alcohol 6 years ago. He eats healthy and exercise regularly.

Resistance to the word diet was seen more often in the non-Aboriginal group. Eleven of 21 non-Aboriginal patients mentioned in conversation that they don't feel as if they're on a diet. Resistance to word diet was found in three Aboriginal men in different contexts and was expressed in different ways. Non Aboriginals openly expressed their feeling that they were not on a diet at all. It seems that the type 2 diabetes diet regime

may have a different connotation for the people who were resistant to it and those who had difficulty following it. Both groups may have a common root to their feelings, a general difficulty accepting the need to change lifelong behaviour though their form of expression is different.

Resistance to the word diet seems to express itself differently between patients. It is possible that some patients express anger (*"I am ready to hit the sky"*), and some express it through passive resistance like *"I eat what my family used to eat"*, or through some form of patient-provider "non-compliance". It's an interesting find that should be further investigated to see if a patient's need for self-protection and "normalization" influences his resistance to the word diet and what would be an adequate way to help him minimize this feeling in order to make behaviour changes more smooth in transition for his overall well-being.

A study on Melbourne Aboriginals showed that: "patients who have less control over what they eat are more likely to eat irregularly and eat whatever is put in front of them or is convenient". This finding was also very prominent in this study. Most Aboriginal patients had a problem with planning meals and cooking food. Food is eaten when one is hungry or when blood sugar goes down.

Only one woman cooks for her and her father and one cooks only when her sons are at home. They both have a great sense of connection to their family. Eating alone seems to be an obstacle in cooking a meal. This may have a cultural connotation but can be understood in the context of disrupted family connections (which was not explored on a deeper level in this study).



In a study (Thomson et al., 2001) “The social and cultural context of risk and prevention: Food and physical activity in an urban Aboriginal community” researchers found that food is often prepared for a large number of family members where the aim is to cook a fulfilling meal, that is, the family meal of meat and vegetables and this may be one of the reason why many Aboriginal women don’t cook when they are alone.

Only one Aboriginal woman spoke at length about her family and how she lost her connection with them and remembering the food that she ate when she was young made her sad when she thought about not being able to eat it again or lead an active lifestyle like she used to (if not necessarily exercise). This example was similar to the one in the Melbourne study.

In this study there was no evidence for the connection between food and close community relationships in Aboriginal patients as in other studies, such as the previously mentioned Melbourne study. This may be due to the line of questioning, or the fact that urban Aboriginals live apart from families and the community, and they either try to adapt to a new lifestyle in the city, or may find themselves in between conflicting cultural values, which may be additional stress for them. One of possible reasons may be living in poverty in an urban setting that doesn’t allow them greater choices and opportunities, either in choosing food or connecting to the family.

Nine out of 15 patients mentioned that they walk for exercise. They said that as an additional comment to explaining their dietary regime and it wasn’t explained in a great detail.

## **4.6. Relative Cost and Type 2 Diabetes**

The relative cost of living with type 2 diabetes can be seen through the lens of monetary, emotional and social costs. The monetary aspect is important in dealing with the disease and may help to facilitate lifestyle changes. Many of the set of complex social interactions that patients go through play an important role in their overall daily living, and may have the power to influence their lifestyle choices. The patient has to adjust to new circumstances and to feel accepted by their family and friends. This is not widely researched in literature, and this thesis will try to better illuminate that aspect of a patient's life.

It was a challenge to separate and extract themes from the whole experience of being a person with type 2 diabetes because each patient has different contexts and relationships towards each participant. These themes were not mutually exclusive, but were intertwined. For instance, it was hard to draw the line between coping and its relationship with food choices or with cost (emotional, monetary) because they all mingle together and give a unique perspective of each individual and their self-perception. In order to create the different themes the researcher undertook a systematic approach to data analysis, going through data several times before conclusively creating them.

## **4.7. Objective 3: Relative Cost for Living With Type 2 Diabetes**

This chapter describes monetary and social costs that people with type 2 diabetes experience. Not all themes were equally significant to the patients. Most patients expressed their concern about the cost of food and that they cannot afford to buy

vegetables and fruit. Most participants said they had to buy certain foods because they are cheaper for them even though they were not good for them but they have to buy certain foods because they are cheaper for them. This was found consistently in the Aboriginal group. Ten out of 17 Aboriginal patients about how their food choices are directly dependent on their income but only 3 out of 21 non-Aboriginal participants talked about same topic.

Food choice map was good instrument that helped patients to talk about their food choices and their inability to buy food. Through spontaneous conversation about their food they choose on a daily basis, many patients felt the need to give more explanations about food cost and their inability to buy certain food. Some were very vocal and some mentioned it quickly during the interview but it seemed to be a very important factor in decision making, particularly in the Aboriginal group.

#### ***4.7.1. Ability to Buy Food***

Ten out of 17 Aboriginal participants talked about the cost of food as a barrier to the improvement of their diets. Explanations of the four Aboriginal participants' who raised this theme are presented first, followed by the examples from the one non-Aboriginal participant's discussions.

Amelia's comment expressed a common problem:

*P: "Food is available. But keeping it in a house on limited income that part... It is more expensive. I cannot afford it. My middle cheque....It cannot keep more than a month. It cannot last a whole month."*

Anthony is on a limited income, "I cannot afford to drink bottled water. I don't drink a lot of water. Unfortunately I cannot afford it." He predicts that food choices would be different if he had more money. "When I go back to work... I'd love to have more vegetables and fruit". He stated that his fear from complications of diabetes and his reduced ability to afford food are main reasons for his food choices. His ability to seek and understand information may be his strengths that are in complete misbalance of his social reality (limited income). It may be hard enough to implement diabetic regime without having to think how to provide for more quality food. It may be forming great conflict in many patients.

Amy lives on a limited income, and that is a big factor in making a decision "Every time I get my check I get roast or barbequed chicken, the whole one ." She buys a meal when she gets her check, every two weeks ("I have to put some meat in there.")

Amelia's food choices are based on a very low income and the fact that she cannot have all her food on a regular basis. "I'll have oriental noodle I used to have those, I had those almost every day because they're cheap eh, but I found out they are very high in sugar, (Laughter) I can't keep enough vegetables in the house I mean yeah. I can't always afford them." The price and what she likes to eat is a big part of her decision making process. "No, no, on a regular basis. I'll get a check every second week. If I buy fish I don't buy so often because it's expensive. I like mustard better. Mustard is cheaper. Mustard is cheaper. Sometimes I buy garlic, cheap".

Abby buys food from paycheck to paycheck and with humor mentioned that she would like her vegetables to be fresh, although it is understandable that she needs that check to buy vegetables.

*P: I always buy that salad in the bag I mix it with tomatoes and cucumbers. Its not often that I get money, not very often. I guess every second week, because I except...my amount is every second week. Maybe I'll buy pees, corn, canned vegetables, beats, corn, that ehh..I: How often? Every two weeks I guess (laughter) because vegetables don't last eh...why?*

Annabelle said she is buying her food because it's cheap: potatoes, pasta and sandwiches although she knows they are not good for her. "Pasta is really cheap and potatoes main things that I know I eat a lot of that I shouldn't". She said that she drinks a lot of Pepsi (4 glasses a day). She does have fruit but rarely because she said that she cannot afford it.

*P: Which food you think is healthy? And pasta I shouldn't be eating but I do. I use to eat a lot of rice I don't eat a lot of rice hardly ever... Just because its cheep. Its really inexpensive you know and basically my diet goes what I can afford, you know.*

*She answered a question regarding using the recommendations from the Centre:*

*I: You couldn't use the information? P: I tried, I still try but .....*

*I: Why you think is hard?*

*P: Because I just buy tings that are available to me like potatoes are cheep, you know I don't buy any white bread at all. I don't use white flours we everything is whole wheat. I: So you are using some information yeahh. Pasta is really cheep and potatoes main things that I know I eat a lot of that I shouldn't.*

There is evidence that food cost directly influence decision-making process in Aboriginal group. This may put high pressure on their decision making process, and according to their respond it is very important reason. This may be conflicting situation for patients that are expecting to choose healthy food and to maintain weight, while they struggle to buy food on a limited income, struggle depression and fatigue and don't have enough support.

Most people in Non-aboriginal group are senior citizens and depend on their pension. They didn't say that their food choices were mainly dependent on their income. Most of the time they stated that their food choice is dependent on what they like to eat or

what are they are used to, or is convenient for them. They might look for the sales, and choose different stores to buy their food, but generally didn't directly depend on the cost of food. This is one example which is not typical but not uncommon:

*P: IGA is too expensive to me and Safeway I hardly ever go there. If they say buy one get one well you know what they have cases of soup if its on sale I buy by case and they say buy one get one you know. So we went there and they want 8\$ or 9\$. I went to manager I say this I crazy we are not we are paying for both of them because we went for super and they got them for 5 \$. I am buying one and getting on it should be for 5 \$. They don't say nothing but I don't know if people understand when they are buying. You gotta watch I am telling you to watch. haaa or they have by this roster or buy this or that and get one. You are paying for it. I am telling you. They are fooling you.*

Some mentioned that their income meets their needs:

*P: Don't know .Luckily I don't know I don't keep track of it.*  
It is reasonable, it is not expensive. I got money in the bank.

#### ***4.7.2. Living Alone***

Three participants explained why it is not easy to live alone. Explanations of the three Aboriginal participants' who raised this theme are presented. Abby: "When you are alone you cannot cook a meal. When my boyfriend is there I eat with him."

All patients were uncomfortable talking about social support when asked about it. They were reluctant to talk about their social support by avoiding the answer or just talking about something else. In conversation, when food choices were brought up they would mention that they live alone or that they don't socialize.

Amelia mentioned:" From time to time my neighbor brought me treat but then it doesn't happen very often. ( Laughter). She brought tea biscuits, they are almost like cinnamon buns but don't have cinnamon on it. More than one time, but not so often. She didn't talk about her support system. "Yeah but I mean....".

Abby “compromises” with her boyfriend, who is helping her with food preparation “When you are alone you can’t cook a meal. When my boyfriend is there I eat with him”. She depends on the help and meal preparation abilities of her boyfriend. Her family doesn’t support her. “ I am not close to my family, if you know what I mean.” Abby would like more social support but with a humor mentioned “No one to cook for me (laughter”)

Amar tried to explain that it is in his family tradition that people are offered food when they come. But he said that people want to offer you food if you are diabetic (“We feed people when they come. Just my auntie, she feeds me. My cousin... They don’t feed you.” When asked: ”Is that because of the diet? Yeah...” He didn’t feel like offering an explanation. He said that his son support him by cooking a food. Only sometimes he said:” my son and his friend they eat. I get hungry nothing all gone they like peanut butter; they eat it 4 times a day. They don’t feel like not cooking they have peanut butter”.

#### ***4.7.3 Alcohol and Friends***

Quitting alcohol was raised from 10 patients and was mentioned though conversation although it wasn’t asked. It was obviously something that most participants were ready to share and was important to them. It is very closely connected for patients with their social life and they were mentioning it in through relation to their friends. Explanations of the two Aboriginal participants’ who raised this theme are presented

Ana doesn’t drink any more and she said :( “I don’t have a social life. Most of my friends drink and stay out of it. I have to. I stay away from drinking so I stay away from

friends too. I am with my dad or go back to work”). Arman said that he doesn’t drink anymore and that caused he and his wife doesn’t socialize anymore.

Two Aboriginal women talked about their addiction to alcohol. Annabelle feels guilty of drinking but still binge drink over the weekends with her best friends. She is aware that she should quit but still not ready. It seemed that she would have to sacrifice her friendships for better choices. Quitting alcohol was important theme for Aboriginal group and obviously one that concern their social connections and friendships.

*I: Beer? yea I like my beer.*

*P: I’ll say maybe once every 2 weeks. I could start actually I can plan o meeting my girlfriends and we gonna go and do something I ill say we gonna have coffee but I know what were like when we come together we gonna end up drinking 5,6 in the morning and then sleep all day.(laughing) but that’s how we are.*

*I: You would like to change that?*

*P: Because when I do drink like that yeeah I have also have regrets later. I spend my money foolishly, we buy marihuana we smoke marihuana I don’t even like that. My mom always told me stay away from that it’s witchcraft it’s evil and I’ll do it anyhow regret that and I make stupid mistakes when I drink, but that’s my social life. I don’t have social life other then when I drinking with my friends. My boyfriend doesn’t drink he doesn’t smoke; he doesn’t t do drugs he doesn’t t go to the bars.*

She explained how her boyfriend doesn’t approve her drinking:

*P: He stay away from me when my family is around when I am with friends he is mad with me so the only time when I socialize is when I drink with my 2 girlfriends and that’s it. We are at home we are not at bar, we are at home and that is basically it.*

Non-Aboriginal patients didn’t talk about alcohol in relation with their food choices neither raise this issue at all.

#### **4.7.4. Family**

Aboriginal patients often mentioned that their family is not living in a city or that they are not close to the family. It was not something that they were not comfortable



talking about but it came in some parts of the interview when they were talking about their food choices. When asked about family Allen said that he doesn't have any family support: "No. Doesn't talk to my family. So, no, no".

Only one Aboriginal woman lives with her father and is very dependent on her father for the support. Her father supports her: "When I go to work, and it's kinda funny because I was on holidays, I'll have my breakfast because my dad always makes me. He made sure that I have cereal and stuff like that so if I wouldn't be eating properly". She mentioned that he supports her, but that he doesn't understand how serious diabetes is: "My father thinks diabetes is nothing (laughter) that I am. He doesn't realize its seriousness. He figures I am taking too many pills and he should be the one taking them, he is older."

Several patients have mentioned that their family members are coping with diabetes too and they can hardly support each other because it is hard for them too. Ann wasn't talkative through the whole interview but when her family was mentioned, she doesn't talk about her diabetes with her family.

She is remembering times in her life when she was at home and had regularly eating moose and fish but she doesn't eat that way anymore ("I left home when I was 21 and all that change because it its not available to me and I am the only one here and my family is down there still and I don't see them...but when they do they do bring me its not often but that its not something that we can put here as a diet. Once in a while, maybe every 3 months I'll get some fish. Once a year I get good chunk but that's it").

*P: If I was at home we had fish maybe 6 times a week for lunch for super sometimes, we'd have our moose meat for supper most of the time and 5, 6times a week. We'd have duck and rabbit , that would be main. I don't eat like that I use to.*

*This example shows how disconnection with the family and cost of food influence he choices:*

*I: Is that because of diabetes or you want to cut some food?*

*P: No that's the way I am I don't. My son will eat everything he as good diet where as me I am picky like hamburger I don't like sausages, pork I like chicken and maybe once in a while I'll have if I am lucky I'll splurge on a stake once a month or two. No I don't like meat if I can eat fish every day I would, like fish from back home like I use to. I'll eat fish every day. But I cannot afford that. (laughing)*

Non-Aboriginal patients didn't mention their families often and when asked about family and social support they would answer shortly and continue talking about other topics. There was an overall response from patients which indicated that they don't need any social support. Many of them didn't want to talk about that or they would just avoid the question altogether by changing the subject or it would come up at different parts of the interview when they were not asked directly. Many live alone and they wouldn't generally comment on their social support.

They felt mostly interested in explaining why they choose to eat certain foods and their weight management. It was difficult to conclude if they were receiving support or not due to a lack of evidence to support either. It didn't seem like something they wanted to share. Only one of the older patients that lives in a home mentioned that she has a big family that supports her:

*P: My husband died this year January, But he had Alzheimer's he was in a personal care home. Nursing all the time. But now I am alone so. My girls are very good, I have daughters they are... My oldest not so much, because she owns a business she is busy...27 employees huh...so. and she likes to play golf. But she phones me all the time. ...always, they come once a week and they take me for any appointments I need to go to, so they are really good. But they have kids too. They've got I've got seven grandchildren and 10 great grandchildren. Two of my granddaughters are on university. And for special occasion my birthday some... 50 of them last time wholly??? She has a steady boyfriend: she is second year university I said I don't want any more kids. (laughter)*

#### 4.7.5. Social Life

Social life was rarely discussed in conjunction with diabetes:

*P: I don't bother too much with people. I socialize but not that much you know. yea. Since I am in wheelchair I seldom go anywhere else's home. It can I have so much other things that I would say that diabetic diet has no impact on my social life. Being in wheelchair and this and that much more..... o.k.*

Older Non-aboriginal women mentioned:

*P: Well we are too old, when we were younger we used to go every Saturday to the club you know, we use to have dancing, we have artist you know, they cut out now there is no dancing we quit going to the club because its drinking you know and we better watch. I don't drink. Away I use to sit with one beer (laughing) I didn't touch any liquor. I don't want it.*

Only two patients, Norman and Nadia connected their social lives with the difficulty in living with Diabetes:

*P: You've got to be careful what you eat today and you go some place don't be too greedy and eat too much. Because someone offered you cannot and you are not suppose to and I don't have it home and I don't and I'll have it. No... To make people happy have a little bit of taste.*

One of the questions about changing lifestyle was answered:

*P: I think so yea I t does in a way I make my own insulin when they come up with pen and I know lady she has to give herself a needle in between the game...it is ...when people sit around its not the thing to do but....ah if you are out in a restaurant or something.. you have to have a needle.(explaining how he makes needle)you know how to ...have proper and ....*

#### 4.7.6. Discussion of Relative Cost for Living With Type 2 Diabetes

The third objective of the study was to document the relative cost that patients experience in dealing with common environmental determinants that act as barriers to improving their health. This study showed that the relative cost of living with the disease was to family, the ability to buy food, and social life.

The lack of the ability to buy food was mostly seen in Aboriginal patients which, in the majority of cases was found to be the greater portion of the reason for not being able to buy more vegetables and invest in healthier food choices. Many of the patients are on a disability pension, or belong to low income families, and it seems that their choices are limited by their modest income. Most senior patients didn't talk about being unable to buy food but mentioned that they keep a close watch on cost and hunt for the best prices of food. Alcohol was mentioned by a few Aboriginal patients as a way of socializing, and that desisting in the behaviour would lead to the loss of friends. Most patients did not find it difficult to quit alcohol consumption but had difficulty dealing with the social ramifications.

The patients gave the impression that they independent of a social support system were not interested in talking about it. Many of them are senior citizens that live alone or live with their sick and older partners, but did not express a desire to discuss it further. The topic may be an area of sensitivity, or the patients have adjusted to the new lifestyle completely.

Their social life came into play in connection with their explanations of their lifestyle choices. There is evidence that it is hard for some patients to avoid certain food choices at social occasions and that there are feelings of awkwardness associated with administering insulin injections publicly.

## CHAPTER 5: GENERAL DISCUSSION

Many themes were identified throughout the course of the study, the most unexpected of which was a resistance to the use of the word diet during the interview process. It is possible that the reason for this reaction stems from the patients' idea that they are not on a diet but are just making healthy choices and eating right as described to them by their dietitian). Patients that felt more in control of the disease expressed a higher level of "resistance to the word diet". Being resistant to the word diet may exist due to a fear of losing control and the existence of external pressure. The patient doesn't feel different if he doesn't have to be on some sort of diet. If the word diet isn't mentioned then they might not perceive themselves as sick, or they would feel no different than people living without the disease. On the other hand it is possible that they feel more externally controlled by health care providers and are not prepared to give up their freedom to make choices.

The psychological reactance theory explains the motivational state that arises when an individual has perceived that his or her freedom is endangered and controlled. Perceived loss of freedom can occur as an action meant to convince an individual to adopt a new behaviour or engage in a new action (e.g. implement medical regimen) as well as to request the abandonment of existing behaviour (e.g. restrict one's diet) (Christensen, 2004). When an individual feels that their behaviour is limited or endangered, their desire for that behaviour increases.

According to the reactance theory the greater the perceived importance of the freedom the greater the motivation of the individual to re-establish the freedom. Discouraging an individual from partaking in activities that are deemed to be threatening

to their health will have a “boomerang effect” as the individual will be induced to participate in the behaviour with even more fervour. This theory receives very little recognition in adherence literature. The patient may wish to restore a sense of control by taking part in the restricted behaviour or refusing to adapt a prescribed behaviour. They may feel angry towards the health care provider whom they identify as a threat to their freedom. There is some evidence that type A’s are angrier towards their illnesses than other patients (Rhodewalt & Marcroft, 1988).

It can be argued that people who feel in control are not always in a position of positive disease management; their confident attitude can give a wrong overall impression. Their confidence may be a self-defence mechanism which allows them to deal with day-to-day life. These patients showed more resistance to being on a diet and were clearer on which foods they liked and disliked. They showed that they believe strongly in themselves and the knowledge that they possess, even though their actions may not always coincide with their positive attitude.

On the other hand, people who talked more about their problems, either emotional and/or social, were usually more open to sharing the difficulties of living with type 2 diabetes. The affordability of food played a major factor in the decision making process of these patients as well as disorganized and unpredictable meal planning which may be a result of getting a monthly pay check which indicates when they can have either more or less food. It can be opposite situation, that due their psychosocial problems(depression, and “unpredictable” life situation, may lead to more self-neglect, and more disorganized meal planning , and affordability of food is adding factor to overall hard psychosocial circumstances. Taking responsibility for their own self-care could possibly be expected

from others (many of them are dependent on a partner or family member who will prepare meals for them and take care of their responsibilities).

The loss of the freedom to make choices may be the root reason that causes people to feel angry or resistant to someone “telling them what to do”, or to feel fearful or depressed regarding their food choices and daily activities. This also represents a possible social cost to living with type 2 diabetes.

The secondary question of this study was to compare Aboriginal and non-Aboriginal patients in the way they perceive their type 2 diabetes management. The Aboriginal group talked about their fears of hypoglycemia and the complications of type 2 diabetes that led them to make different food choices. This group admitted to having less social support and expressed less resistance to using the term “diabetic diet”. They seemed only moderately or not at all concerned about weight management. In contrast, the group that felt more in control felt that they could manage their weight if they decided to, or that they had good results with weight management in the past. The value they placed on weight maintenance suggests that it plays a key role in their disease management.

A recurring and prominent finding was that many Aboriginal patients reported that they cannot afford the food that dietitians advise them to eat. For them to buy vegetables and fruits regularly is a recurring difficulty. The patients spoke more openly about their difficulties in life, in which the disease was just another negative factor. Emotional coping, not having a regular exercise regime, and irregular eating habits were reported more often by the Aboriginal participants.

The difficulty in applying certain facets of type 2 diabetes management (weight control, regular exercise, and healthful eating habits) in the Aboriginal community seems to stem from the difficulty of dealing with the disease individually as opposed to the possibility of community support and an active lifestyle as a result of family based living. Some findings indicate that urban Aboriginal patients seem to have a problem eating alone, generally don't have a lot of support from family and friends, and seem to have a form of reliance on other people to cook for them or to have someone "remind" them about their diet. This may relate to separation from their families and traditional systems of support which allowed for a community based approach to healing as opposed to individual determining lifestyle choices. Garro, (1994). The system may create a feeling of security as an entire community becomes responsible for the well being of a single person as opposed to feeling guilty for making personal decisions that have a negative effect on a family or community at large. Although in some Aboriginal communities people don't tell their families of their diagnosis or don't like to talk in front of family about diabetes (there is an one example from this study too), this may be more "rudiment" behavior in urban Aboriginals that are "disconnected" from land and family for generations.

Different support system is possible needed for different patients. For patients that feel in control attention should be given to providing them with enough health information, helping them modify their diet in a "gentle" way so they don't feel threatened or angry when explaining the role of diet and exercise in managing type 2 diabetes. It may be helpful to advise them on ways to use food that they like (not recommended by dietitian) sparingly. Attention should be given to their own views on



how to deal with their choices and provide them with the information gradually. Patients should be supported in collaborating with their health providers.

People with more emotion reaction may need more emotional support, and more counselling and social support. Depression and fatigue should be controlled , therefore more intrinsic motivation would help patients deal with the disease management. It may be crucial for some patients to help them with organizing their exercise routines and planning meals. Workshops that can help people on low income to make alternative healthier meals may be needed. They should be advised and informed about possible financial assistance programs from federal, provincial or territorial funding. The message from health care team may be crucial in showing that they care and support them all the way.

## CHAPTER 6: CONCLUSION

This thesis examined lifestyle choices in type 2 diabetes patients. The evidence from the study shows that the psycho-social dynamic that affects a patient's management is multifaceted. Many themes are identified and many reasons for lifestyle choices are uncovered. The identified themes include: "maintenance of weight," "maintaining weight and desire for foods," "food as temptation," "fear of diabetic complications," "depression," "fatigue and tiredness," "resistant to diet," "trust in health care professionals," "family tradition: cooking," "unfocused eating and food preferences," "just eating normally", "ability to buy food," "living alone," "alcohol and friends," "family," and "social life."

Many of the patients who felt that they controlled their diabetes felt that they had a greater control over their lifestyle choices in general: diet and exercise. Weight management seemed to be a very important aspect of their disease management. Desire for certain foods and food appeal seem to be an obstacle for some. A resistance to the diet regime was recognized as a possible way for patients to protect themselves and to be able to have some autonomy within the decision making process, or to act as a factor in psychological "normalization."

Some patients spoke more about the physical and emotional burdens of type 2 diabetes like being depressed or fatigued. A surprising number of patients (Aboriginal) said they were not able to provide enough food for themselves due to a limited income and were dependent on a small weekly check to provide for their needs. Their choices were greatly dependant on their low incomes. Most patients didn't have enough social support or didn't rate it as important to them. It seems that the patients brave the

adversities of living with type 2 diabetes despite very difficult circumstances.

Consequently, lifestyle choices in patients were perceived differently based on their income, education, co-morbidities and specific lifestyle circumstances.

The main rationale for this study was to gather information and interpret the data that will lead to the recommended changes of services aimed at the improvement of clinical disease management outcomes. The information gathered in this study provides us with greater insight on the reasoning behind a patient's choices, coping mechanisms and the cost of living with the disease. The data contained in this thesis may allow for the implementation of new management and coping strategies designed around and with sensitivity to type 2 diabetes patients.

The specific outcomes that came from this research are:

1. Recognizing the control that patients already exert over their choices;
2. Recognizing social cost for living with type 2 diabetes:

Psychological (depression, fear of complications,)

Dietary challenges (resistance to diet, temptation for certain food,  
unfocussed eating and food preferences)

Food insecurity for Aboriginal patients

## **CHAPTER 7: FUTURE RESEARCH**

Further research is necessary to determine which decision-making processes patients with type 2 diabetes use. In conclusion, an intervention study may be designed to try to use the conclusions from this study. It may be possible to work with people that are trying to manage their disease so that they can implement their dietary and exercise goals, interpreting possible resistance. It would be geared towards trying to work with people with other needs (emotional, social) more closely, organizing social services and psychological counselling with regularly organized workshops on different topics that promote more holistic and integrative approaches to health care.

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# **APPENDICES**

## **9.1. INTRODUCTORY LETTER TO RESPONDENTS**

### **Diabetes and Food Choices Study**

Explanations for potential study participants

People from the University of Manitoba have prepared a study about the ways that patients with diabetes manage their disease.

I am asking whether you would be interested to join this study.

It is an hour interview about your food pattern and other health-related choices in your daily life. You can get your own results afterwards, if you wish. Your help would make it easier to improve the food and health advice that we give to patients with diabetes.

Are you willing to be contacted about the study?

## 9.2. DEMOGRAPHIC QUESTIONNAIRE

DEMOGRAPHIC INFORMATION: Ref. No. \_\_\_\_\_

>

Instructions: Please complete the following background information by filling in the blanks or circling the best answer that describes your response.

> Age: 18-25    26-35    36-45    46-55    56-65    66+

> Weight: \_\_\_\_\_ Height: \_\_\_\_\_

> Gender:    Male    Female

> Marital Status:

>    \* Single

>    \* Married (Excluding Separated) or Common Law

>    \* Divorced/Separated

>    \* Widowed

>    \* Other: \_\_\_\_\_

> Ethnic Background/Area of Family Origin:

> Location of immediately related family:

> Type of transport used on a daily basis:

> Date of last visit to physician:

> Frequency of visits to any health service over the last 6 months:

> Level of Education:

>    \* Grade 8 or less

>    \* Some high school

>    \* Completed high school

>    \* College certificate or diploma

>    \* Some university



- > \* Completed university
- > \* Post-graduate training
- > \* Other (specify \_\_\_\_\_ )
- > \* no response

> Language most frequently spoken at home:

- \* English
- \* French
- \* German
- \* Italian
- \* Ukranian
- \* Ojibway
- \* Cree
- \* Other (specify \_\_\_\_\_ )
- \* no response

> Number of people living at your home, including yourself: / \_\_\_\_ / \_\_\_\_ /

> Number of children under the age of 18 living at your home: / \_\_\_\_ / \_\_\_\_ /

- >How secure is the job?
- >Have you been in this job for a long time?
- >Do you expect to stay in this job?
- >Does the income meet the needs?

### 9.3. FOOD CHOICE MAP INTERVIEW QUESTIONS

#### Food frequency

1. What food do you eat most often?
2. When in the day do you usually eat that (mentioned) food?
3. Which meal(s) or snack(s) does the food usually belong to?
4. What other food do you usually eat at this meal or snack?
5. How often during a week do you eat these mentioned foods during this meal/snack?  
Do you eat these foods more or less often, or the same number of times as the first one?
6. What other meals or snacks do you eat during the day?

Repeat the next 2 questions for every meal and snack the interview person agrees that this is the food pattern for one week.

7. What food do you usually eat at this (newly mentioned) meal or snack?
8. How often during a week do you eat these mentioned foods during the meal or snack?

#### Food Choice

9. In regards to the first food you mentioned, are there other foods that could take its place in that meal?
10. How often do you eat this alternative foods-more often, less often or as frequent as the food you first mentioned?
11. Are there alternative choices for each of the foods in their respective meals?

12. Why do you actually choose the first mentioned food more often than the alternative food(s)?
13. The foods you eat most often are very important for you, why?
14. Which meals or snacks do you eat alone or with others?
15. Who do you eat with?
16. What the relationship are the people to you?
17. How often do you eat this meal (snack) with these persons?
18. Do you share the money for the foods/meals? With whom? Who contributes?
19. Who decides what foods will be purchased?

#### Food preparation

20. Where is the meal prepared (ask for every meal of the day)?
21. Do you prepare meals alone or do you have help?
22. How often do you prepare meals each day?
23. Where do you buy your food?
24. Who decides which foods will be purchased? What are the criteria?
25. Have you recently changed the amount or type of food(s) you eat? Why?
26. Did the amount increase or decrease, and by how much for the consumption of any of these foods/meals? Why?
27. Are you planning to change the amount of any foods you eat? – which ones? – Why?
28. Where do you get the information on the best buys, what is in the food, how healthy it is?

29. Do you feel you have to wait for the decision of any person before buying or spending money? – which person?

#### Diabetes Management Education Use

These questions will be asked if the respondent made reference to using the education program. If no reference is made to information or service use, then these questions will be eliminated.

1. Documenting the reason that some patients with type 2 diabetes are not able to control diabetes with life-style choices.

Which food is healthy (which food is not healthy)?

Have you changed your diet? (How do you know to change? Who explained you what you would need to change?

What information do you hear from the Centre?

Do you use the information in your daily life?

Can you follow the nutrition recommendations you receive at the Centre? If so, in what way? If not, why not?

Do you follow the nutrition and health information you hear from others? If so, why?

Do you ever receive any advice on blood glucose monitoring at the Centre? Do you practice it?

2. Documenting the reasons individuals have for their life-style choices, including food choices, physical activity and a range of social behaviours.

Why do you eat this food more often than that food?

Do you need to lose/gain weight?

Do you exercise?

Do you prepare recommended diet yourself? If so, why? If not, why not?

What is for you the hardest recommendation to follow?

Does your new diet change your social life? If so, why? If not, why not?

Does your family support your new recommended diet and exercise?

3. Documenting the relative costs that patients experience in dealing with common environmental determinants that may act as barriers to improving their health.

Is this new recommended diet difficult to get?

Is it more expensive than the food you usually buy?

#### **9.4. RESEARCH PARTICIPANT INFORMATION AND CONSENT FORM**

**Title of Study: “Lifestyle choices of patients with Type 2 diabetes”.**

**Principal Investigator:** Milena Pirnat  
Health Action Centre  
425 Elgin Avenue  
Winnipeg, MB R3A 1R9

Phone: (204) 940 3839

You are being asked to participate in a research study. Please take your time to review this consent form and discuss any questions you may have with the study staff. You may take your time to make your decision about participating in this study and you may discuss it with your friends, family or (if applicable) your doctor before you make your decision. This consent form may contain words that you do not understand. Please ask the study staff to explain any words or information that you do not clearly understand.

##### **Purpose of Study**

This research study is being conducted to study the reasons that patients with Type 2 diabetes have for their lifestyle choices and for dealing with the disease. It will also document how easy people find it to make those choices routinely, such as food choices, physical activity and social activities. The main purpose is to find out whether groups of patients, such as aboriginal and non-aboriginal, differ in the way they control the disease with various health-related behaviors. 40 people will participate in this study.

### **Study procedures**

You will be asked to fill in a questionnaire with some personal information, such as your age, education, skills, language and expenditure categories for major living costs. You and an interviewer will go through an in-depth interview, which includes creating a visual representation of your typical food pattern in a usual week. The interviewer will use information on the map to prompt for related behaviors and talk about social and economically related information.

The questions and answers will be tape-recorded. The Demographic Questionnaire and the Food Choice Map will be completed at the same meeting in a private location in the Health Action Centre. The total time to complete the two instruments will be one hour. You can stop participating any time in the event that you feel uncomfortable about answering the questions. However, if you decide to stop participating in the study, we encourage you to talk to the staff first.

### **Risks and Discomforts**

There are no risk or benefits associated with participating in this study. During the conversation you may have other feelings about foods or diet than the ones we talk about. If any of these would be uncomfortable for you, then you can stop the conversation and, if necessary, you can discuss any issue with the staff of the Health Action Centre.

### **Benefits**

There may or may not be direct benefit to you from participating in this study. You can benefit from seeing the analysis of your own information, which is available to you on request. We hope the information learned from this study will benefit other people with Type 2 diabetes in the future.

### **Costs**

All the procedures, which will be performed as part of this study, are provided at no cost to you.

### **Payment for participation**

You will receive \$ 15 for taking part in this study.

### **Confidentiality**

Information gathered in this research study may be published or presented in public forums, however your name and other identifying information will not be used or revealed. Despite efforts to keep your personal information confidential, absolute confidentiality cannot be guaranteed. Your personal information may be disclosed if required by law. The University of Manitoba Health Research Ethics Board may review records related to the study for quality assurance purposes.

All data will be destroyed after the study is published or after two years, whichever occurs earlier. None of the data is stored by name, only by ID number. The list of names will be destroyed after the data collection and analysis is complete.

All data, including paper transcripts and tapes, will be destroyed by shredding. Computer files will be overwritten and deleted.



### **Voluntary Participation/Withdrawal from the Study**

Your decision to take part in this study is voluntary. You may refuse to participate or you may withdraw from the study at any time. Your decision not to participate or to withdraw from the study will not affect your care at this centre. If the study staff feels that it is in your best interest to withdraw you from the study, they will remove you without your consent. We will tell you about any new information that may affect your health, welfare, or willingness to stay in this study.

### **Questions**

You are free to ask any questions that you may have about your treatment and your rights as a research participant. If any questions come up during or after the study, contact Milena Pirnat at (204) 940 3839. For questions about your rights as a research participant, you may contact The University of Manitoba, Bannatyne Campus Research Ethics Board Office at (204) 789-3389. Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions.

### **Statement of Consent**

I have read this consent form. I have had the opportunity to discuss this research study with Pirnat Milena. I have had my questions answered by them in language I understand. The risks and benefits have been explained to me. I understand that I will be given a copy of this consent form after signing it. I understand that my participation in this study is voluntary and that I may choose to withdraw at any time. I freely agree to participate in this research study.

I understand that information regarding my personal identity will be kept confidential, but that confidentiality is not guaranteed. I authorize the inspection of any of my records that relate to this study by The University of Manitoba Research Ethics Board, for quality assurance purposes. By signing this consent form, I have not waived any of the legal rights that I have as a participant in a research study.

**Participant signature** \_\_\_\_\_

**Date**

\_\_\_\_\_

**Participant printed name:** \_\_\_\_\_

\_\_\_\_\_

**I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has knowingly given their consent**

**Printed Name:** \_\_\_\_\_ **Date**

\_\_\_\_\_

**Signature:** \_\_\_\_\_

**Role in the study:** \_\_\_\_\_

**PARTICIPANT INITIALS:** \_\_\_\_\_

Lifestyle choices of patients with type 2 diabetes

16 October 2002

## 9.5. EXAMPLE OF COMPLETED FOOD CHOICE MAP

### FOOD CHOICE MAP

RESPONDENT #: 2

DATE: Aug 30, 02

LOCATION: HAC

INTERVIEWER: Liana Pinat

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	1x / Week	2x / Week	3x / Week	4x / Week	5x / Week	6x / Week	7x / Week
<b>TIME</b>							
<b>EARLY (1)</b>		Eggs	Banana Milk Cereal				Yogurt
<b>SNACK 1 (2)</b>							
<b>MID DAY (3)</b>					[Food Icon]		[Food Icon]
<b>SNACK 2 (4)</b>							[Food Icon]
<b>END OF DAY (5)</b>	Rice [Food Icon]	[Food Icon]	[Food Icon]	Potatoes [Food Icon]			[Food Icon]
<b>LATE (6)</b>							

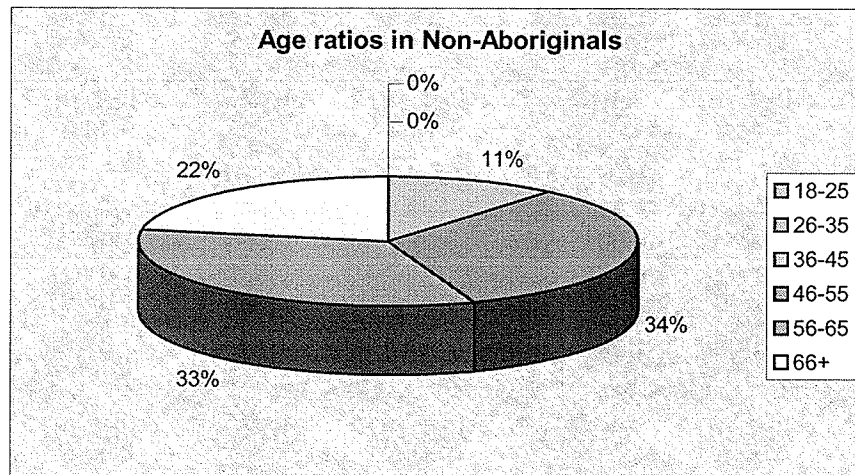


Figure 1.1. Age ratios in Non-Aboriginals

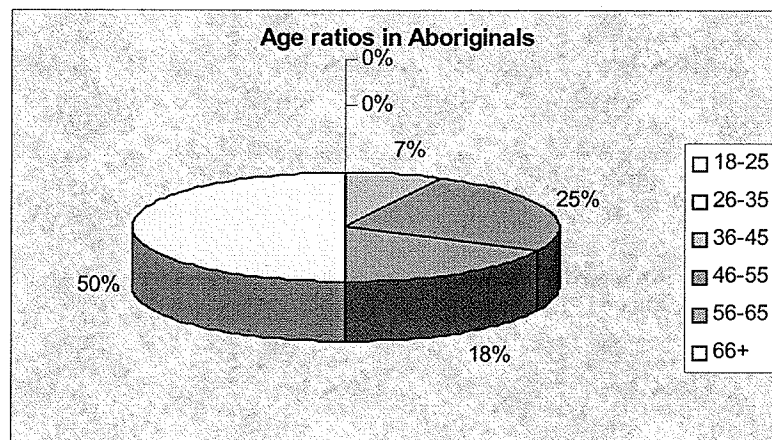


Figure 1.2. Age ratios in Aboriginals

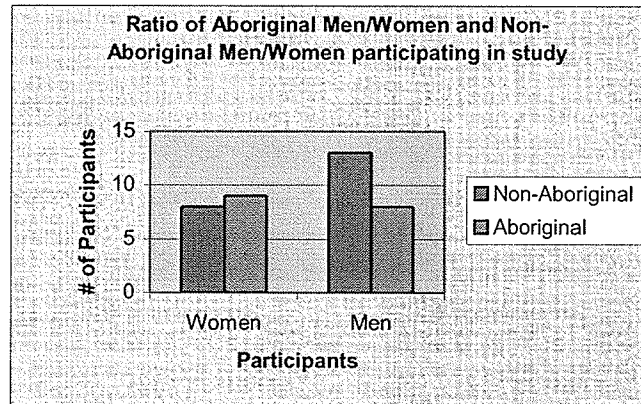


Figure 1.3. Ratio of Aboriginal Men/women and Nonaboiginal Men/women participating in a study

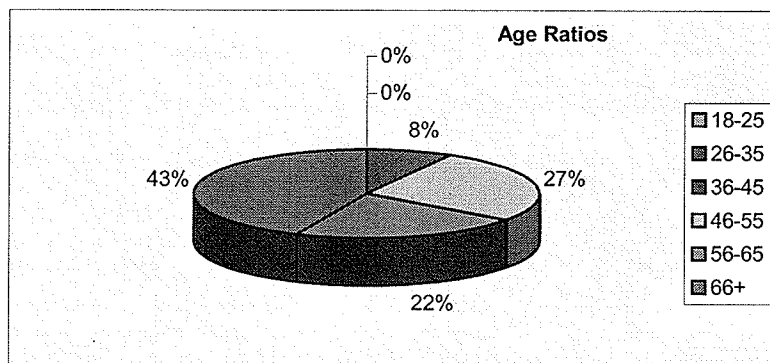


Figure 1.4. Age ratios in study population

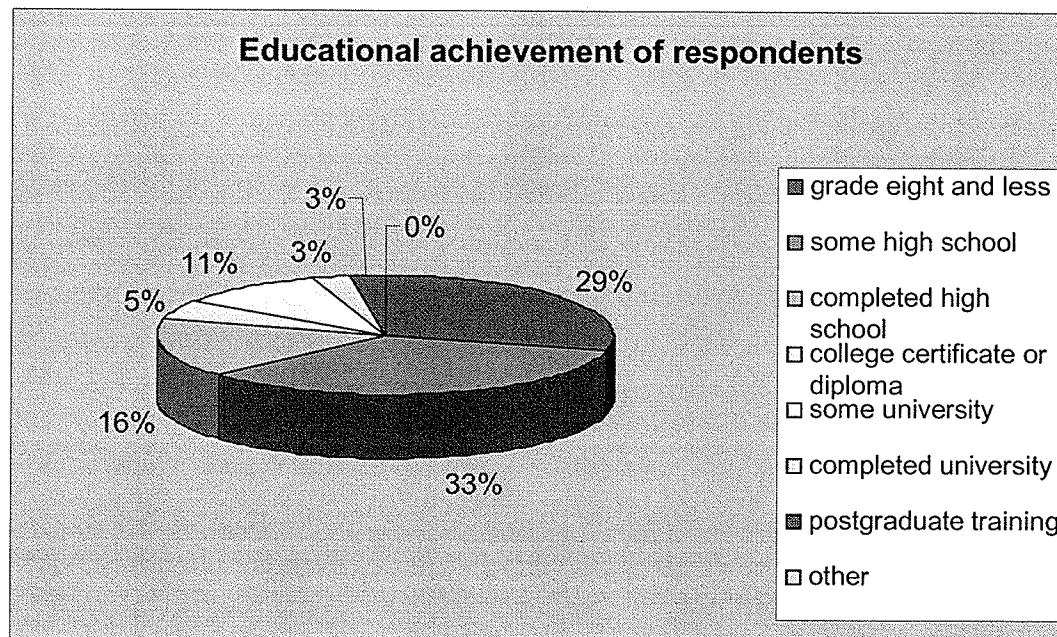


Figure 1.5. Educational achievement of respondents

**9.6. TABLE OF MAJOR CONSTRUCTS (DEFINITIONS, RECOGNITION AND FUNCTIONS)**

	Definition	Recognized	Function
1.Coping	Refers to cognitive and behavioral efforts to master, reduce, or tolerate the internal and/or external demands that are created by the stressful transaction (Folkman & Lazarus, 1980; Lazarus & Launier, 1978).	Patients were communicating how they feel and how they manage their life with Diabetes	<i>Patients</i> used it to control distressing emotion, or are used to control decision making and direct action.
1.1.Fear	It is fear of complications of diabetes	Patients freely expressed their feelings of fear	It was linked on how it affect people on every level and how patients link it in their worlds(as motivator for change or barrier to improving their regime)
1.2.Depression	It is mental state of powerlessness and haplessness	Patients talked openly how they feel	Unmotivated to make changes
1.3. Fatigue and tiredness	Patient feel weak and tired when performing activities	Patients talked openly how they feel physically	Barrier to self care
2. Perception of control	They trust what they learn and they are trying to implement it.  <i>Control</i> as a coping process refers to cognitive and/or behavioral efforts to exercise or seek control (Wong & Sproule, 1983).	Perception of control was measured through the way people strongly communicated idea that they exercise and try to implement the diet, or even resist the diet (seen of a way to control their own lifestyle choices). Their answers are clear and they are sure of themselves	Patients that felt that they are controlling what they eat, exercise and that what they do is the best that they can do in that moment.
2.1. Resistant to diet	Patients view their diets as separate and	Patients expressed it openly though	Expressing control and anger

	independent from prescribe diet	conversation or it was obvious in conversation that they were resisting the question	
3.1. Food choice approaches	Patients view of their food choices approaches	Patients expressed it through talking about their food choices (Food choice map)	Barrier or ability to make food choices
3.1.1. Unfocussed attention	It is inability to focus attention on which food to choose in the moment when you have to decide.	Patients talked about eating spontaneously without planning or focusing on food choice	Barrier to make different food choices
3.1.2. Focused attention	It is ability to focus attention to food choice	Patients talked about ability to focus on making the food choice	Ability to make different food choices
3.2. Maintaining weight	Refers to patient perception about weight management	Patient talked about their weight management	Barrier/ability to control weight
4. Alcohol and friends	Patients state that alcohol is in correlation with social life(friends)	Patients spontaneously mentioned alcohol in correlation to friends	Barrier to social life
5. Family	Patients view family as part of their social support system	Patients talked openly about family and support	Barrier or support to changing lifestyle
6. Reduced affordability of food	Patient state that they are not able to afford certain food	Affecting their food choice	They believe that this is barrier to improving their dietary choices
7. Living alone	Patient expresses inability to engage in personal care	Cannot cook a meal	Barrier to self care

\* An important feature of this definition is that coping is denned independently of its outcome. That is, coping refers to efforts to manage demands, regardless of the success of those efforts. The effectiveness of any given coping strategy is not inherent in the strategy