An exploration of the impact of cultural food beliefs and attitudes on the acceptance of the dietary recommendations for Type 2 Diabetes.

by

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Abstract

Title: An exploration of the impact of cultural food beliefs and attitudes on the acceptance of dietary recommendations for Type 2 Diabetes.

Objectives: The purpose of this research is to discover culturally shared local beliefs and attitudes towards foods that may impact the acceptance of dietary recommendations for the management of Type 2 Diabetes (T2DM) amongst Ojibwe (Anishinabek) in M'Chigeeng First Nation.

Methods: Culturally-appropriate grounded theory research using focus group discussions with Anishinabek community members with Type 2 Diabetes Mellitus residing in M'Chigeeng First Nation in the Manitoulin District Ontario.

Results: Four focus groups were conducted with a total of 21 participants. Four global themes emerged from focus group discussions 1) Diabetes as colonizing agent, 2) The diabetes diet is an unnatural way of eating, 3) Diabetes takes away pure cultural experience, 4) Anishinabek family is key to successful diabetes management.

Conclusions: Recognition by diabetes educators and diabetes stakeholders that diabetes and its dietary guidelines may be perceived as at odds with cultural identity and well being is an important consideration when working with Anishinabek community members with diabetes. Working in collaboration with community members with diabetes to protect cultural identity and a greater focus on family integration may lead to greater success in diabetes dietary self-management.

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Table of Contents

List of Tables

List of Figures

Chapter One: Introduction

1.1 Purpose

The purpose of this research is to discover culturally shared local beliefs and attitudes towards foods that may impact the acceptance of dietary recommendations for the management of Type 2 Diabetes (T2DM) amongst Ojibwe (Anishinabek) in M'Chigeeng First Nation. Additionally, the purpose of the research is to;

1. Explore the perceived relationship between traditional foods and T2DM.
2. Explore the influence of cultural gatherings and ceremonies on food consumption/choices and nutrition management of T2DM.
3. Explore family dynamics and its influence on the dietary management of T2DM.

1.2 Objectives

The objectives of this research include the following;

1) To critically examine the current literature related to attitudes and beliefs of Aboriginal people towards food, particularly of Aboriginal people with T2DM
2) To conduct focus groups exploring the attitudes and beliefs about foods of Aboriginal people with T2DM.

3) To identify cultural beliefs and attitudes that promote and hinder healthy eating amongst Aboriginal community members living with T2DM.
4) To make recommendations based on findings to improve diabetes nutrition education and cultural competence of diabetes educators.

1.3 Significance

Manitoulin District has the highest rates of T2DM in Ontario (Hux & Tang, 2002). The high prevalence rate, 9.58% (age and sex-adjusted), is to a great extent attributed to the large Aboriginal population on Manitoulin Island. Positive lifestyle changes, including diet and physical activity, are important factors in the management of diabetes. The Canadian Diabetes Association (2008) supports the use of ethnic-specific community based diabetes management programs as there is recognition that there is a complex relationship between cultural context and lifestyle. It is recommended that diabetes education programs for Aboriginal populations consider various learning styles, incorporate local traditions and cultures and promote traditional foods and practices provided they are safe, acceptable and accessible (Canadian Diabetes Association, 2008). Gaining a better understanding of local nutrition beliefs and attitudes towards food through this research may lead to the development of improved approaches to self-management education that are locally relevant. Additionally, a better understanding of cultural beliefs and attitudes towards foods may be used to improve cultural competence of diabetes educators working with Aboriginal community members with diabetes.

1.4 Definitions

Definition of Aboriginal persons

The term Aboriginal people in the past has generally applied to persons resident in Canada who could trace their origins to the indigenous people who inhabited the area of what is now Canada when the first Europeans arrived (Statistics Canada, 2006).

The Canadian Constitution recognizes three groups of Aboriginal people –Status Indians, Métis people and Inuit. These are three separate peoples with unique heritages, languages, cultural practices and spiritual beliefs (Indian and Northern Affairs Canada, 2001a). The term 'First Nation' came into common usage in the 1970s to replace the word 'Indian', which many people found offensive. Although the term First Nation is widely used, no legal definition of it exists. Among its uses, the term "First Nations peoples" refers to the Indian people in Canada, both Status and Non-Status. Inuit, is defined as the Aboriginal people in northern Canada, who live above the tree line in the Northwest Territories, Nunavut and in Northern Quebec and Labrador (Indian and Northern Affairs, 2001a).

Definition of traditional foods

Traditional food includes all foods within a particular culture available from local natural resources that are culturally acceptable. Historically, the Aboriginal peoples subsisted off of the land procuring food by hunting, gathering, fishing, trapping (Kuhnlein, Receveur & Chan, 2001;

Willows, 2005). Synonyms encountered in the literature may include "Bush Foods", "Native Foods", "Indian Foods", "Country Foods" or more specific terms denoting Aboriginal ancestral membership and the term "Foods" following, such as "Cree Foods".

Definition of culture

Culture is defined as the ideas, customs, and social behavior of a particular people or society (Oxford Dictionary, 2011). In the context of this study culture refers to the shared patterns of behavior, beliefs, attitudes, values and language of the Ojibwe (Anishinabek) people.

Definition of cultural competency

Cultural competence is a "set of congruent behaviours, attitudes, and policies that come together in a system, agency, or among professionals and enable that system, agency, or those professionals to work effectively in cross-cultural situations." (U.S. Department of Health and Human Services, 2007). Cultural competence in health care practice reduces disparities in health services, increases the detection of culturally specific diseases and promotes a safe and comfortable environment for First Nation, Métis or Inuit patients within the health care system (National Aboriginal Health Organization, 2003; Nova Scotia Department of Health, 2005).

Definition of cultural safety

Cultural safety moves beyond the concept of cultural sensitivity and awareness to analyzing power imbalances, institutional discrimination, colonization and colonial relationships as they

apply to health care (NAHO, 2008). The concept of cultural safety originated in New Zealand from work done by Ramsden (2002) in the field of nursing which has later spread to other fields and countries.

Cultural safety within an Aboriginal context means that the educator / practitioner / professional, whether of Aboriginal decent or not, can communicate competently with a patient in that patient's social, political, linguistic, economic, and spiritual realm (NAHO, 2008). A culturally unsafe practice can be understood to mean —any actions that diminish, demean or disempower the cultural identity and well-being of an individual (Nursing Council of New Zealand, 2002). Cultural safety requires that health care providers be respectful of nationality, culture, age, sex, political and religious beliefs, and sexual orientation. Cultural safety is the outcome of culturally competent care (NAHO, 2008).

Definition of social norm

Social norm, is a pattern of behavior expected within a particular society in a given situation. The shared belief of what is normal and acceptable shapes and enforces the actions of people in a society. Those who do not follow their social norms are considered eccentric or even deviant and are typically stigmatized. The very fact that others in one's society follow the norm may give members of a specific society a reason to follow it (Oxford Dictionary, 2006).

1.4 M'Chigeeng First Nation

M'Chigeeng First Nation is an Aboriginal community situated on Manitoulin Island, Ontario (See Figure 1.1). It is originally an area settled by the Ojibwe tribe and remains to this day a predominately Ojibwe community. Anishinabek, is the enthnonym (the name a group gives itself) often used by the Odawa, Ojibwe, and Algonkin peoples, and will used for the remainder of this study to refer to the particular Aboriginal group in M'Chigeeng First Nation. Demographic characteristics, access to health care services and sources of nutrition education that may affect health beliefs and health knowledge are reviewed in this section. Additionally the food systems available to the community are also considered.

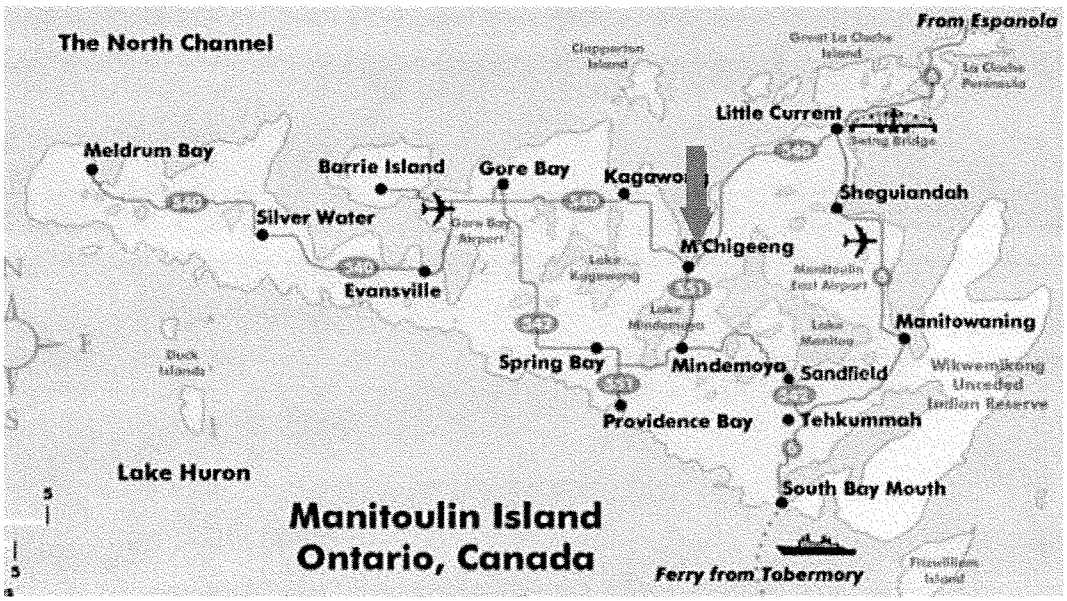

Figure 1.1: Manitoulin Island, Ontario, Canada, map

Population demographics

According to M'Chigeeng First Nation band office records the on-reserve population in M'Chigeeng First Nation as of January 2011 is 887 community members, which includes both Aboriginal and non-Aboriginal persons (Valerie Beaudin, personal communication, February 2nd 2011). As displayed in Table 1.1, between 2001 and 2006 M'Chigeeng First Nation's on-reserve population grew from 729 to 766 community members, a growth rate of 5.1%, below the provincial average for the same time period, of 6.6%, (Statistics Canada, 2007; Statistics Canada, 2002). Of the 2001 Census data, 96.5 % of the community claimed Aboriginal status, with 30 non-Aboriginal persons in the community. The median age is 33.0 years of age, significantly younger than the provincial median age, of 39.0 years. The proportion of persons over the age of 15 is 70.5 %, comparatively less than the national average of 80.9 % (Statistics Canada, 2002). The younger population demographics are likely attributed to a combination of the higher birth rates seen amongst Aboriginal populations and a lower life expectancy (Indian and Northern Affairs, 2001b; Statistics Canada, 2007).

	M'Chigeeng First Nation (on-reserve pop.)	Ontario
Population in 2006	766	12,160,282
Population in 2001	729	11,410,046
Population change (%)	5.1	6.6
Aboriginal ancestry	725 (95.4%)	242,490 (2.0%)
Median age (years)	33.0	39.0

Table 1.1: Population and Age Characteristics, M'Chigeeng First Nation (Statistics Canada, 2006)

Employment and income

The community had an unemployment rate nearly three times the provincial average, with 18.2 % of the labor force unemployed in 2001 (Statistics Canada, 2002). Even higher was the 26.7 % unemployment amongst the male population 15 years of age and over (Statistics Canada, 2002). In 2006, the unemployment rate improved to 12.5%, almost twice the provincial and national unemployment rate (See Figure 1.2) (Statistics Canada, 2006).

Of the 310 persons with earnings in 2006, approximately 46.8% worked full time, the remainder working part time. The median total income of persons 15 years of age or older in M'Chigeeng was $12,672.10. This was $11,932 less than the provincial average of $24,604 (Statistics

Canada, 2006). Of this income 27.2% came from government transfers rather than personal income, in comparison to 9.8 % for the rest of Ontario (Statistics Canada, 2006). Lower average income earnings and high rates of social assistance suggest high rates of poverty that impact on the ability of some community members to procure nutritious foods for themselves and their families.

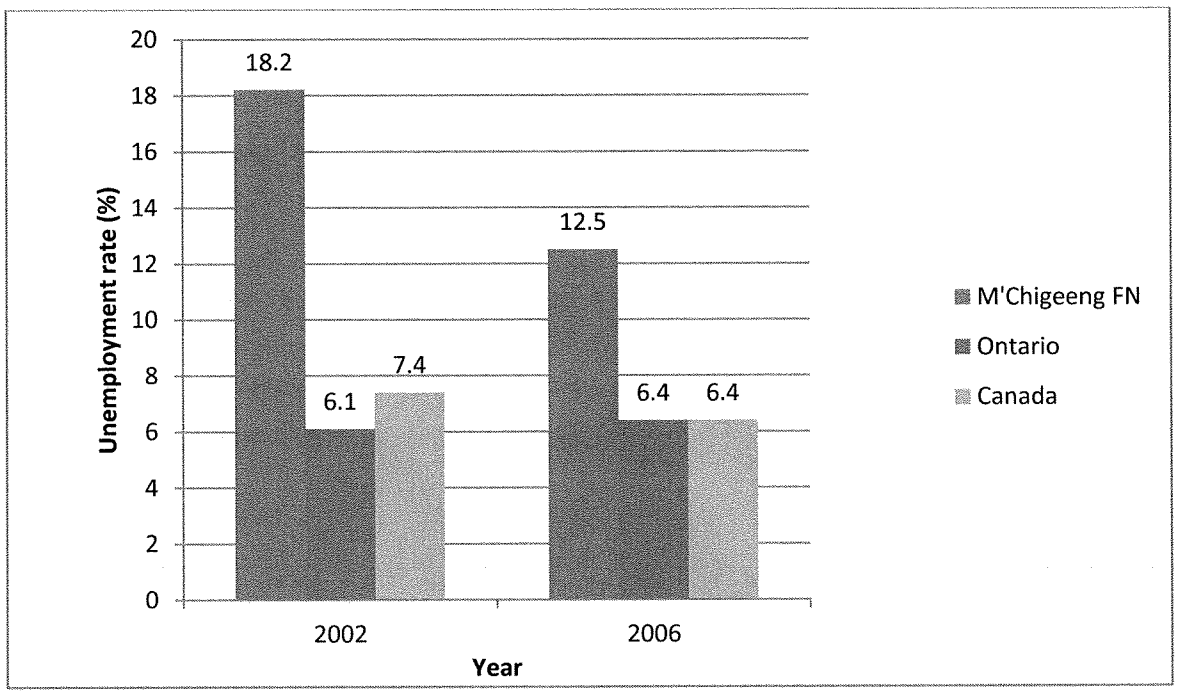

Figure 1.2: Unemployment rate comparisons, M'Chigeeng First Nation, Ontario, Canada (Statistics Canada, 2002; Statistics Canada, 2006)

In 2005, 36.6% (75 families) of the 205 families on reserve were lone-parent families, more than twice the provincial average of 15.8% (Statistics Canada, 2006). Parents in these lone parent families had a lower income, $24,128/ annually, than couple-families on reserve, $38,633, and also less than lone-parent families in Ontario ($34,206) (*ibid.*). The prevalence of lone parent

families means lone parents may have less time for meal preparation if they are working and decreased time for positive modeling of food behaviors. Furthermore the economic realities of lone-parent families on reserves put this group at particular risk of food insecurity.

Over a quarter (27.2%) of on-reserve income is derived from Government transfers (Statistics Canada, 2006).The special diet allowance (SDA) is a social assistance supplement provided to eligible Ontario Works and Ontario Disability Support Program (ODSP) recipients. The SDA is intended to provide financial assistance with the cost of a special diet for recipients who have an eligible medical condition for which a special diet is generally considered necessary by the Ontario medical community for treatment of the medical condition. The maximum monthly payment is $250; however amendments made on December 2005 have made it more difficult for individuals with special diet requirements, including diabetes, to receive the maximum monthly payment (Ministry of Community and Social Services, 2005). Currently SDA recipients are awarded an allowance based on the number of eligible medical conditions requiring a "special diet". Each eligible medical condition is assigned a reimbursement rate and the rates are additive to a maximum of $250. For example diabetes is an eligible medical condition that is awarded a maximum monthly payment of $42 / month. Individuals receiving reductions in their SDA would have to either cut back on their food budget or cut into their other sources of social assistance which may have been marked for housing, bills, clothing, utilities or other necessities.

Further reforms to the SDA program are scheduled to take effect April 1st 2011 for new applicants and July 31st2011 for existing SDA recipients. The proposed amendments will further decrease the number of applicants eligible for the maximum allowance. The new SDA guidelines

have categorized eligible medical conditions into related disease categories. Where individuals have more than one eligible medical condition within one category they are only awarded one allowance. Previously awards for eligible conditions were additive regardless of whether medical conditions were related or not. The Ministry of Community and Social Services' move to reduce the number of applicants receiving the maximum SDA is ill advised as continued rising food costs will further put a strain on individuals and families who rely on social assistance to provide healthier diets. With a more limited food budget individuals may relay on lower quality food items which may have a negative effect on diabetes control and ultimately the health status of these individuals.

Education

A demographic characteristic that may influence health literacy and health beliefs is level of education attained. Health literacy refers to people's capacity to obtain, process and understand (written or oral) health information and services to make appropriate health decisions (Ratzan & Parker, 2000, as cited in Peerson and Saunders, 2009). A relationship has been demonstrated between low literacy levels and declining use of available health information and services (DeWalt, Berkman, Sheridan, Lohr, & Pignone, 2004). In other chronic disease models, inadequate health literacy was associated with suboptimal health beliefs about chronic disease (Federman, Wisnivesky, Wolf, Leventhal & Halm, 2010) and less knowledge pertaining to the chronic disease (Gazmararian, Williams, Peel & Baker, 2003). Schilinger et al. (2002) found that patients with inadequate health literacy were less likely than patients with adequate health

literacy to achieve tight glycemic control, were more likely to have poor glycemic control and to report having retinopathy.

Nutbeam (1999, as cited in Peerson & Saunders, 2009) proposes a three tiered concept of health literacy; functional health literacy, interactive health literacy and critical health literacy. Functional health literacy is the most relevant level for individuals with lower levels of attained education. Functional health literacy includes basic tasks such as reading consent forms, patient labels and inserts, and understanding written and oral health care information provided by multi-disciplinary health professionals, as well as acting upon necessary procedures and directions (e.g. medications, appointment schedules) (Dewalt et al., 2004).

According to 2006 Census data a larger percentage of the on-reserve M'Chigeeng First Nation population had less than high school education (40.2 %) than the provincial (22.2%) and national averages (23.8%). Within all age groups this difference in less than high school attainment educational attainment persisted (ages 25-34: 22.2 % vs 8.6 %; ages 35-65: 30.6 % vs 15 %) (See Figure 1.3) (Statistics Canada, 2006). The 2001 iteration of the Community Survey noted that amongst males ages 45-65 years of age 45.5% had less than high school graduation; suggesting that a large portion of middle aged and elderly men may be particularly at risk of low health literacy (Statistics Canada, 2002).

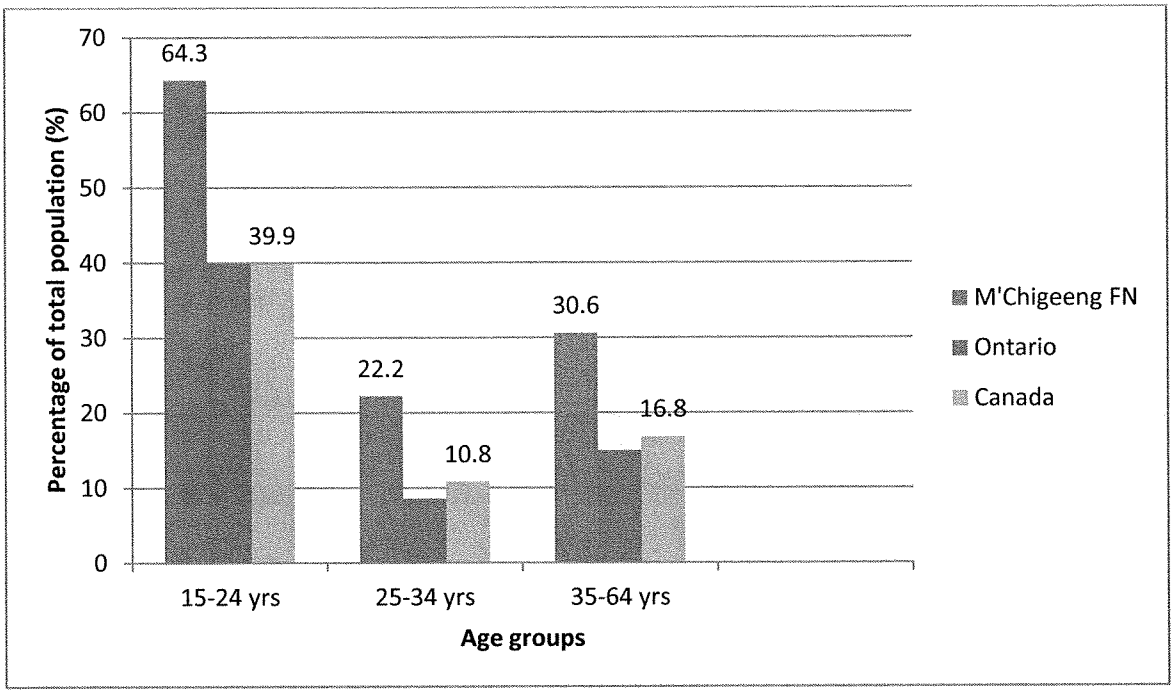

Figure 1.3: Educational attainment, Percentage of population with less than high school certificate, M'Chigeeng First Nation vs Ontario vs Canada (modified Statistics Canada, 2006)

All age groups had significantly smaller proportion of the population with university degrees (ages 15-24: 0.0% vs. 7.3%; ages 25-34: 11.1% vs. 32.7%; ages 35-64: 8.1% vs. 24.0%) (See Figure 1.4) (*ibid.*). This segment of the population may be the greatest resource in interpreting health information yet there are a smaller proportion of these highly educated persons in the on-reserve population.

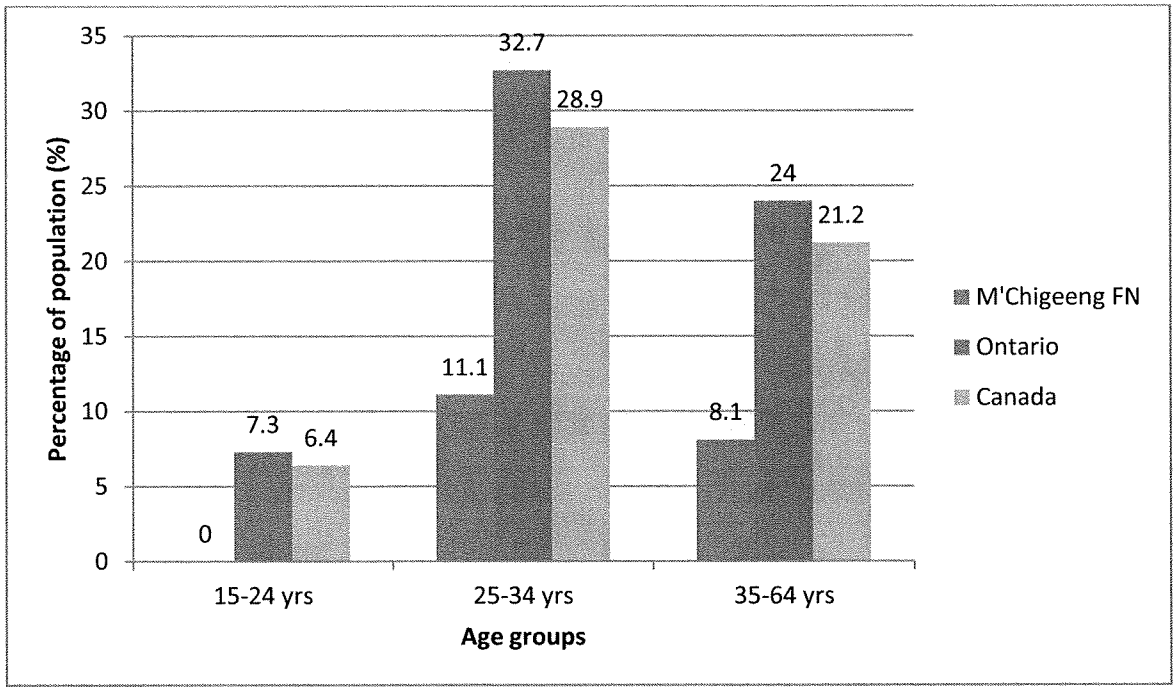

Figure 1.4: Educational attainment, Percentage of population with University certificate, diploma or degree at Bachelors level, M'Chigeeng First Nation vs Ontario vs Canada (modified Statistics Canada, 2006).

Despite this there is a significant proportion of the M'Chigeeng First Nation population with college diplomas (20.5%), which is comparable across all age groups to province wide rates (ages 15-24: 7.1% vs. 9.9%; ages 25-34: % 27.8% vs. 24.3%; ages 35-64: 25.8% vs. 21.3%) (*ibid.*). This high proportion of college graduates could be a product of the proximity of Cambrian College to the community and its positive working relationships with First Nation communities.

Limited health literacy has been identified as a key contributor to disparities in health outcomes and has been associated with poor diabetes self-care (Kim, Love, Quistberg & Shea, 2004).

With lower levels of educational attainment in nearly all levels of education and age categories community members with T2DM are at risk of having lower levels of functional health literacy and thus be at risk of disparities in diabetes outcomes.

Access to health care

M'Chigeeng First Nation has a Community Health Centre situated on highway 551 near Mindemoya Lake, in what is known as the Lakeview area of the reserve. It provides primary health care services to M'Chigeeng band members and those residing on the reserve.

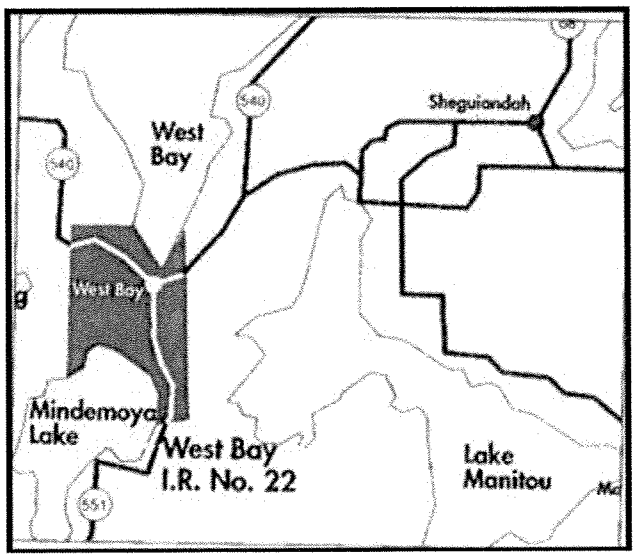

Figure 1.5: M'Chigeeng First Nation (formerly West Bay, I.R. No. 22)

Ten community members identified themselves as working in a "Health Occupation" in 2001 (Statistics Canada, 2006). This constitutes 2.7% of the labor force in the health care field, while in Manitoulin District and Ontario 8.6% and 5.3% worked in the health care field, respectively (Statistics Canada, 2006). This suggests less health care capacity within the community than

outlying communities. Indeed, having community members in health care industry is a valuable source of health literacy for the community (Shah, 2003). Due to the few health care professionals residing in the community the health centre relies on external organizations to provide a large portion of the professional health care needs of the community. For example, the Mindemoya Family Health Team provides physician services. Noojmowin Teg Aboriginal Health Access Center, a decentralized health centre serving seven First Nation Communities, provides regular nurse practitioner, psychology, dietitian and diabetes education services.

Two local hospitals are situated within the district; Mindemoya Hospital (8.2 km) and the Manitoulin Health Center (31.3 km), serve the needs of local area residents for emergency, primary care, inpatient services, and some diagnostic needs including those in M'Chigeeng First Nation.

Diabetes

No formal diabetes prevalence research has been conducted at this time. Currently, M'Chigeeng First Nation is partnered with researchers at the Northern Ontario School of Medicine as a participant in Diabetes Research that may benefit the community (Maar, McGregor & Sutherland, 2007). V. Beaudin, M'Chigeng Diabetes Educator, estimated that approximately 126 community members are afflicted with diabetes (V. Beaudin, personal communication, February 17th, 2010). With this number of identified community members with diabetes the estimated prevalence rate of T2DM on-reserve is 14.2 %.

Food procurement

In the town proper, food procurement is limited to two small convenience stores; West Bay General Store and Paul's Corner Store. Mindemoya Foodland, a medium sized, grocery store is located 8.7 kilometers away. The distance to Mindemoya Foodland may be a barrier to procuring a variety of high quality foods. Lautenschlager & Smith (2006) found that compliance to a diabetic diet was hindered because participants had difficulty accessing high quality, healthful foods with no major grocery stores nearby.

The health disparities between the Aboriginal population and mainstream Canada have been well established (Romanow, 2002). The social determinants of health model has provided researchers an understanding of the contributing factors to the health disparities observed across the Canadian population. One well recognized model includes fourteen social determinants:

1) Aboriginal status,
2) gender,
3) disability,
4) housing,
5) early life,
6) income and income distribution,
7) education,
8) race,
9) employment and working conditions,
10) social exclusion,
11) food insecurity,
12) social safety net,
13) health services,
14) unemployment and job security

(Mikkonen& Raphael, 2010).

Marginalized populations are particularly at risk of having worse self-reported health and health status than mainstream populations (Statistics Canada, 2005). Although it is beyond the scope of this thesis to explore all the social determinants of health of the study population; it is apparent from available demographic information that many community members in M'Chigeeng First Nation face challenges to their health in the areas of Aboriginal status, race, income, education, employment, unemployment, food security, and health services.

2.1 Diabetes Prevalence

Type 2 Diabetes has received the status of worldwide epidemic; the World Health Organization (2006) estimates that more than 180 million people worldwide have diabetes. This number is estimated to more than double by 2030 (World Health Organization, 2006). In 2005-2006, approximately 1.9 million Canadian men and women had been diagnosed with diabetes. This represents about 1 in 17 Canadians, 5.5 % of all women and 6.2 % of all men (Public Health Agency of Canada, 2008). This places a substantial burden on the national health care system for direct diabetes care, as well as the medical care necessary for the higher rates of co-morbidities seen in diabetics. For example, the rates of cardiovascular disease and hypertension are higher among Canadians diagnosed with diabetes. Results from the Canadian Community Health Survey 3.1 indicate that 19.8% of individuals with diabetes also have heart disease, compared with 4.0% among those without diabetes. Similarly, 60.3% of individuals with diabetes in Canada had also been diagnosed with high blood pressure, compared with 17.4% among those without diabetes (Sanmartin & Gilmore, 2006).

Aboriginal Diabetes prevalence

The health of the Aboriginal population is generally viewed as worse than that of non-Aboriginal Canadians. The state of diabetes in the Aboriginal population contributes to this perception with prevalence 1.5 to 4 times that of the national average (Health Canada, 2010; Health Canada,

2001; Martens et al., 2002; Statistics Canada, 2002; Tjepkema, 2002). Prevalence rates differ between Aboriginal communities and across regions. In Manitoba, for instance, the diabetes prevalence (adjusted for age/sex) among registered First Nation peoples is four times higher than that of other Manitobans (18.9% vs 4.3%), while in Whitehorse, in Yukon territory, the prevalence is 5.4 %, only slightly more than the general population (Martens et al., 2002; Statistics Canada, 2002). In 2001-2002, the prevalence of diagnosed diabetes among the James Bay Cree adult population was 15.1%, while the prevalence for British Columbian Aboriginal men and women was 7% (Public Health Agency of Canada, 2008). Amongst off-reserve Aboriginal people recent statistics show a prevalence of diabetes of 8.7% (Tjepkema, 2002).

Aboriginal peoples' susceptibility to diabetes is not solely a national problem as trends in the United States show similarly alarming rates of diabetes in modern day Aboriginal populations. Data from the 2005 Indian Health Service (I.H.S) user population database indicate that 14.2 % of the American Indians and Alaska Natives aged 20 years or older who received care from I.H.S had diagnosed diabetes (National Institute of Diabetes and Digestive and Kidney Diseases, 2008). After adjusting for population age differences, 16.5 % of the total adult population served by I.H.S had diagnosed diabetes, with rates varying by region from 6.0 % among Alaska Native adults to 29.3 % among American Indian adults in southern Arizona (National Institute of Diabetes and Digestive and Kidney Diseases). Schulz et al. (2006) found a 38% prevalence of diabetes in United States-based Pima Indians, the highest known prevalence in the world.

2.2 Diabetes Co-morbidities

Manitoulin Island physicians noted that Aboriginal patients in the district had high rates of poor glycemic control (Maar, McGregor& Sutherland, 2007). This perception by local physicians was later confirmed quantitatively by Maar, Gzik & Larose (2010) who found that Aboriginal patients on Manitoulin Island with diabetes are nearly twice as likely (19.4% vs. 10.9%) to have highly elevated glycemic levels (A1C >8.5%).

Poor glycemic control in diabetes can lead to secondary complications that can affect both the length and quality of life. Studies have found that diabetes associated co-morbidities and complications occur at higher rates than expected within the Aboriginal diabetic population; these include hypertension, obesity, cardiovascular disease, cerebrovascular disease, end stage renal disease, diabetic neuropathy and diabetic retinopathy (Bruce & Young, 2008; Hanley et al, 2005; Shalala, Trujillo, Hartz, & Paisano, 2000). Hanley et al. found kidney disease to be common among a sample of Sandy Lake First Nation members. Kidney damage was evidenced by the high prevalence rates of micro-albuminuria (44%) and for macro-albuminuria (16.9%), both highly sensitive indicators of glomerular disease and a sign that the kidneys are not functioning properly. In addition, early neuropathy was prevalent (46.3%), and 23.3% of the population had some level of retinopathy (*Ibid.*).

According to Maar et al. (2010) the Aboriginal population on Manitoulin Island is diagnosed at a younger age (8 years earlier) than the non-Aboriginal population. This combined with the aforementioned higher proportion of Aboriginal diabetics with uncontrolled diabetes gives

evidence to earlier described observations by Manitoulin Island physicians. The physicians described an extreme and early onset of secondary complications due to diabetes amongst their Aboriginal patients (Maar, McGregor & Sutherland, 2007).

2.3 Aboriginal Susceptibility to Diabetes

The increased susceptibility of Aboriginal people to developing diabetes is not well understood. Many factors have been proposed, each with varying levels of support. These factors include the propensity for overweight/obesity due to an insulin-resistant genotype (Baschettis, 1998; Colagiuiri & Brand-Miller, 1997); transition from a traditional diet to a pre-dominantly western diet (Williams et al., 2001); a sedentary lifestyle leading to increased body mass indexes (Schulz et al., 2006); high birth weight infants (Dyck, Klomp & Tan, 2001); the effects of poverty (Frohlich, Ross & Richmond, 2006); and the effects of colonialism (Richmond, 2007; Frohlich, Ross & Richmond, 2006).

Increasingly poverty is being recognized as a major contributor to the high prevalence of chronic disease, including diabetes (Dinca-Paaitescu et al., 2010; Reading, 2009; Reading & Wien, 2009). Earlier genetic theories of increased prevalence of diabetes amongst Aboriginal populations have largely been discredited (Poudrier, 2007). Dinca-Panaitescu et al. (2010) found that the prevalence of T2DM in the lowest income group is 4.14 times higher than in the highest income group in the general Canadian public. Prevalence of diabetes decreases steadily as income goes up. The likelihood of diabetes was significantly higher for low-income groups even

after adjusting for socio-demographic status, housing, body mass index (BMI) and physical activity.

2.4 Traditional Foods

Prior to Western contact Aboriginal peoples subsisted off of the land; farming, hunting, gathering, fishing, trapping to provide for their nourishment (Kuhnlein, Receveur & Chan, 2001; Willows, 2005). On Manitoulin Island the Anishinabek traditional diet consisted of wild meats and fish; deer, moose, rabbit, bear, beaver, partridge, goose, quail, fish, oysters, mussels and wild plants; including cat tail roots, berries, (cranberries, blueberries, choke cherries, hawberries, strawberries), corn, dandelions, wild chives, mushrooms, squash, various beans, acorns, nuts, seeds, rose hips, edible flowers and teas (cedar, mint, medicinal teas) amongst others (Angela Shawanda, personal communication, March 2nd 2011). Though traditional food-based diets vary greatly across Canada depending on the cultural practices, geographic locations, and species availability; in general the traditional diet tended to be high in lean protein, low in fat and carbohydrate sources were derived from low glycemic index foods. The diet as a whole provided adequate amounts of energy and micronutrients for health and they led an active traditional lifestyle (Broussard, 1994; Thorburn, Brand & Truswell, 1987; Willows, 2005). The importance of traditional food goes beyond mere nutrition; as Aboriginal peoples see it as an important indicator of cultural expression and as having great sociological meaning (Kuhnlein, Receveur & Chan, 2001; Willows, 2005).

2.5 Contemporary Aboriginal Diet

The dietary intake of contemporary Aboriginal people contains both traditional and market foods. Market foods include foods available for purchase at a grocery store / food market. The proportions vary, depending on remoteness from urban centers and the transport system for market foods (Wein, 1995). While the traditional diet is believed to have been mostly nutritionally complete, the current mixed or exclusively western diet of many Aboriginal groups has been found to be incomplete in micronutrients and with skewed proportions of macronutrients. The current diet has been found to be low in iron, folate, calcium, vitamin D, vitamin A, zinc, fiber, fruit and vegetables; high in fat, salt, and sugar intake (Bersamin, Luick, Ruppert, Stern & Zidenberg-Cherr, 2006; DeGonzague, Receveur, Wedll & Kuhnlein, 1999; Lytle et al., 2002; Taylor, Keim & Gilmore, 2005; Wein, 1995; Willows, 2005).

The prominence of a mixed diet and exclusively western diet is evident in some Aboriginal populations and age groups. Children tend to consume less traditional food than adults; and young adults consume less traditional foods than middle-aged adults, who in turn consume less traditional food than elders (Bersmin A., Luick B., Ruppert E., Stern J. & Zidenberg-Cherr, 2006; Kuhnlein, Receveur, Soueida & Egeland, 2004). Bersmain et al. (2006) found amongst a group of Yupi'k Eskimos that the contribution of traditional foods to energy intake increased significantly with age (0%-53% of intake) being the highest in the eldest group in the community. Trifonopoulous et al. (1998) found that only 17.7% of Mohawk students in grades four and six mentioned traditional food in a 24 hour recall. Amongst a third grade group of

Native American children only 7 out of over 1300 of the total food items listed from 24 hour recalls were traditional food items (Lytle et al., 2002).

Amongst a sample of Native American women the top most commonly consumed foods included coffee/tea, soda, butter/margarine, white bread, diet soda, coffee creamer, potatoes, sugar, sugar substitute, and meat sandwich. Snack chips were consumed more frequently than different types of fruit. Beef, bacon/sausage, hamburger, fried chicken were the most frequent meats consumed (Taylor, Keim, Gilmore, Parker & Delinder, 2006). This suggests that if applicable to other communities many Aboriginal community members may have the majority of the diet composed of nutrient poor foods. The choice of foods of lower nutritional quality is likely linked to the affordability of these foods and the poverty experienced by many Aboriginal people who are reliant on these cheaper foods to stretch limited budgets to feed their families.

The 2010 Nutritious Food Basket, a public health survey tool that measures the cost and affordability of basic healthy eating, found that it costs about $171 a week ($740 per month) to feed a family of four (two parents and two children) in Sudbury and Manitoulin districts (Sudbury District Health Unit, 2010). For a single mother with two children this amount was $561.00 per month. For many people in the Sudbury and Manitoulin district the cost of buying healthy food does not fit into the household budget.

The affordability of a healthy diet varies from region to region in Ontario (See Table 2.1). While the cost of the NFB in Sudbury and Manitoulin was below the average cost of the NFB in northern regions surveyed ($783.47/month) for a family of four, it was well above the average

cost of the NFB in Southern Ontario ($720.94/month) and the NFB provincial average ($733.07/month) (Middlesex-London Health Unit, 2010).

City/district	Family of four	Single parent household, with 2 children	Single person household
Hamilton	$690.59	523.26	230.70
London and Middlesex county	$699.65	n/a	$216.11
Ottawa	$723.00	$548.00	$241.00
Sudbury and Manitoulin District	**$740.00**	**$561.00**	**$248.00**
Toronto	$715.28	541.73	226.24
Thunder Bay	$789.97	$597.36	$265.26

Table 2.1: Nutritious Food Basket survey, selected cities and regions, 2010 (City of Hamilton Public Health Services, 2010; Ottawa Public Health; Sudbury District Health Unit, 2010; Thunder Bay District Health Unit, 2010; Toronto Public Health, 2010)

The transition from a diet consisting of exclusively traditional foods to that of market foods, many of which are of low nutritional quality, is thought to be a major contributing factor to the increased prevalence of diabetes amongst the Aboriginal population (Baschetti, 1998; Thorburn et al., 1987; Schulz, Bennett, Ravussin, Kidd, Kidd et al., 2006; Williams et. al, 2001).

Schulz, Bennett (2006) found that amongst a genetically similar group of Pima Indians, with sharply contrasting lifestyles there was a 5.5 times lower prevalence (age and sex-adjusted) of diabetes in a Mexican based group (6.9%) that adhered to a traditional diet as opposed to a community of U.S. Pima Indians (38%) that led a 'Western lifestyle' (38%). A longitudinal study that followed a small group of Pima Indians over a ten year period found that those that followed a "Western" diet were 2.5 times more likely to develop diabetes upon follow-up than those that followed a traditional diet; those following a mixed (western and traditional) diet were 1.3 times as high as the traditional diet group (Williams et al., 2001). Wolever et al. (1997) demonstrated that a diet high in protein and low in dietary fiber intakes were associated with an increased prevalence of newly diagnosed diabetes in the Sandy Lake, Ontario Aboriginal community, independent of age, sex, and Body Mass Index (B.M.I.). The lower fiber choices made by the newly diagnosed diabetics is indicative of a higher intake of refined carbohydrates not typical in the traditional diet. Carbohydrate in traditional diets has been shown to be absorbed more slowly than western refined foods and it is suggested that it may once have been protective against diabetes (Thorburn, Brand & Truswell, 1987). In fact, in a study comparing the rate of carbohydrate absorption of traditional foods 23 out of 30 traditional "bush foods" studied were digested significantly more slowly than western foods (Thoburn et al., 1987).

A successful research and education intervention program with one British Columbia Aboriginal community demonstrated that increasing traditional food use can improve health status for vitamin A, iron and folic acid in the Aboriginal population (Kuhnlein, Receveur & Chan, 2001). Even in those with diabetes high traditional food usage may have a protective effect. In Bella Coola Valley, a lower than expected prevalence of cardiovascular disease co-morbidities was

found in a group of Bella Valley diabetic Aboriginal community members, which was attributed to the frequent consumption of fatty fish, rich in Omega 3 fatty acids (Thommasen, Patenaude, Anderson, McArthur & Tildesley, 2004).

2.6 Health Belief Model

Hochbaum, Kegels, and Rosenstock's Health Belief Model (HBM) was utilized to develop the framework of the present research. The Health Belief Model proposes that cognitive factors, such as attitudes and beliefs, influence an individual's decision to make and maintain a specific health behavior change (Bauer & Sokolik, 2002). The recognition that beliefs and attitudes play an important role influencing lifestyle decisions makes the HBM an appropriate fit for the current study. For the purposes of the current research the model will be modified to be sensitive to understanding the factors affecting dietary choices.

Paramount to this behavior change model to making health behavior decisions are the following beliefs:

1. The individual is susceptible to the health problem.
2. The specific disease can severely impact quality of life.
3. Changing health behavior will reduce the risk of the disease.
4. Barriers to making the behavior change can be overcome with reasonable effort.
5. The individual is capable of making the change (self-efficacy)

(Bauer & Sokolik, 2002)

The concept of self-efficacy, which is a component of many behavior change models including the Health Belief Model, was developed by Albert Bandura and is defined as "our personal belief of how capable we are of exercising control over events in our lives" (Bauer & Sokolik, 2002). Self-efficacy influences whether people even try to develop healthy habits, as well as how much effort they expend in coping with stress, how long they persist in the face of obstacles, and how much stress they experience (Santrock & Mitterer, 2004). Self-efficacy has been found to be strongly linked to diabetes care behaviors and may both reinforce and be reinforced by these behaviors (Rubin, Peyrot & Saudek, 1993).

A related concept to self-efficacy is *locus of control.* A locus of control orientation is a belief about whether the outcomes of our actions are contingent on what we do (internal control orientation) or on events outside our personal control (external control orientation) (Santrock & Mitterer, 2004, p. 468). Locus of control is conceptualized on a uni-dimensional continuum, ranging from *external* to *internal.*

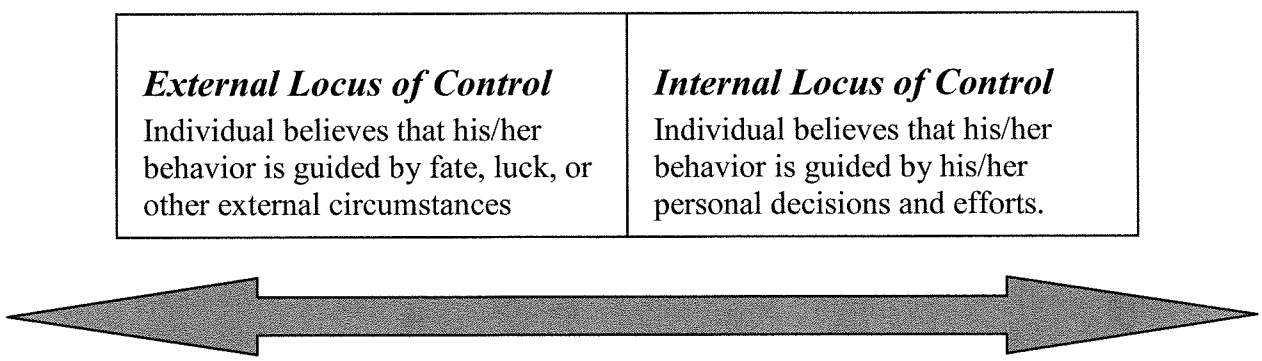

Figure 2.1: Locus of control continuum (modified from, Neill, 2006).

In general, it seems to be psychologically healthy to perceive that one has control over aspects of life which one is capable of influencing (Neill, 2006). A more internal locus of control is thus generally seen as desirable if a person has the appropriate life skills (*ibid.*). Promoting an internal locus of control for Aboriginal people with T2DM may be more difficult than the general population due to the negative effects of colonialism (Alfred, 2009; Maar, Manitowabi, Gzik, McGregor & Corbiere, 2011), social inequality and experiences with poverty (Frohlich, Ross & Richmond, 2006; Herd, Goesling, & House, 2009) that could promote the development of an external locus of control. For example, a patient with an external locus of control may not believe that they can positively affect their blood glucose management through improved dietary habits, 'No matter what I eat my blood sugars go up', and delegate sole responsibility for adequate glycemic control to health care providers, such as their medical doctor.

2.7 Food Beliefs and Attitudes

There is strong support for the effectiveness of nutrition management of diabetes (Pastors, Warshaw, Daly, Franz & Kulkarni, 2002; Pi-Sunyer et al., 1999). National guidelines emphasize the importance of nutrition therapy, and place it prominently with the other important components of diabetes self-management (American Diabetes Association, 2009; Canadian Diabetes Association, 2008). The components of healthy self-management include a healthy diet, self-monitoring of blood glucose, medications, physical activity and smoking cessation (Canadian Diabetes Association, 2008). Clinical practice guidelines highlight the importance of developing problem solving, goal setting and active decision making skills to support self-management behaviors (*ibid.*). However, local attitudes and beliefs towards food and food

choices may be a barrier to prevention and optimal control of diabetes (Boston et al., 1997; Maar, McGregor & Sutherland, 2007). In fact a mutual understanding of appropriate foods for diabetes has been identified as one of the greatest barriers between health care workers and diabetic community members in some Aboriginal populations (Boston et al., 1997).

Contemporary food dichotomy

Qualitative and ethnographic research suggests a dichotomous categorization of foods in many Aboriginal groups; these reoccurring categories are "Traditional Foods" and "Western Foods", with various synonyms in the literature (see definitions section) (Boston et *al.*, 1997; Gittelsohn et *al.,* 1996). Similar findings were demonstrated in a group of Australian Aboriginal people; categorizing food into three groups; family foods (Traditional Foods), fast food and diet food (Western Food).

Traditional food beliefs

Aboriginal people rate the majority of traditional foods with a high health value (Boston et al., 1997; Gittelsohn et al., 1996; Wein, Sabry & Evers, 1989). Traditionally hunted wild game is particularly noted for its high health rating amongst Aboriginal populations (Boston et al., 1997; Wein, Sabry & Evers, 1989). In fact, amongst the James Bay Cree animal fat from wild game was described by Cree study participants as "good" and "nourishing" (Boston et al., 1997). It is believed by many Aboriginal peoples that the restoration of traditional subsistence foods and practices are essential to regain the health of Aboriginal people and communities (Conti, 2006).

Western food beliefs

Studies suggest a belief that "White Man's Food" or "Western Food" consumption is linked to diabetes or poor general health, especially when combined with low consumption of traditional foods (Gittelsohn et al., 1996; Lautenschlager & Smith, 2006; Wein, Sabry & Evers, 1989). Processed high fat, high sugar foods are viewed as having low health value compared to traditional foods and unprocessed Western foods (Boston et al., 1997; Gittelsohn et al., 1996; Lautenschlager & Smith, 2006; Wein, Sabry & Evers, 1989). Packaging and storage of contemporary foods may also decrease the perceived healthfulness of western foods, as freshness has been shown to be a determinant of perceived healthfulness in Aboriginal populations (Gittelsohn et al., 1996).

Though western processed foods are viewed to have a lower health value than traditional foods, some segments of the Aboriginal population have differing opinions. Older Aboriginal adults in one study rated chocolate bars, soft drinks, potato chips significantly higher than did younger people (Wein et al., 1989). Participants commented that these foods must be good for health, since children thrive on them (Wein et al., 1989). The authors suggested that older adults may have a limited ability to distinguish health value amongst foods in some communities (*ibid.*).

Meat, fish and poultry

Strong local beliefs of the primary importance of meats in the Aboriginal diet have been noted across many Aboriginal populations. Large portions of meat, such as caribou or moose, were

viewed as desirable amongst three Aboriginal communities in the Yukon (Wein; 1996). Meat has been found to be considered the main feature of meals amongst James Bay Cree (Boston et al., 1997) and Northern Ontario Ojibwe-Cree (Gittelsohn et al., 1996). Fatty meat from goose, bear, duck, beaver, caribou, and fatty fish were considered "good Cree foods" and "important in a healthy Cree lifestyle". The animal fat from wild game was described as "good" and "nourishing" (Boston et al., 1997). Wild meats available to the Ojibwe (Anishinabek) in North Eastern Ontario would come from predominately deer, moose, and rabbit, which are notably leaner than the more common meats found in traditional Cree diets.

Vegetables and fruit

There is variability of Aboriginal peoples' perception of health and attitudes towards fruits and vegetables. In general, fruits and vegetables, including store bought, are believed to have high health value (Gittelsohn, et al., 1996; Wein el al., 1989). Less is known about Aboriginal attitudes towards starchy and non-starchy vegetables. Boston et al. (1997) found an unfavorable attitude towards non-starchy vegetables. A Cree respondent stated that "People tend to spend their money on chicken or beef. Vegetables are sort of last". Amongst a sample of three Aboriginal communities living in the Yukon some store-bought foods such as potatoes, tomatoes, and lettuce, more frequently appeared on a perceived ideal diet list than on an actual dietary recall list (Wein, 1996).

In spite of the perception of healthfulness of fruit for the general population there was confusion as to how fruit, particularly "sweet fruits" fit into the diabetic diet, as some Aboriginal people grouped bananas, apples, oranges as "junk food" due to their sweet taste (Gittelsohn et al., 1996).

Talyor et al. (2006) found that vegetables and fruit were not commonly consumed amongst a sample of Oklahoma Native Americans. For example, out of the fifty most frequently reported consumed foods green salad, broccoli and cauliflower, carrots, and green beans ranked 29th, 31st, 39th and 47th, respectively. This is compared to the top ten most frequently consumed foods; coffee/tea, soda, butter/margarine, white bread, diet soda, coffee creamer, potatoes, sugar, sugar substitute and meat sandwiches.

Studies have shown that perceived health value of foods, such as vegetables and fruit do not translate to frequent consumption (Taylor, 2006; Wein, 1996). In remote and Northern communities high cost, poor quality, lack of variety and lack of availability have been cited as barriers to the purchase of fresh vegetables and fruit (Willows, 2005). Unfavorable attitudes and beliefs towards vegetables and fruit combined with low intakes may be associated with poorer glycemic control (Savoca, Miller & Ludwig, 2004).

Dairy

Attitudes and beliefs towards milk and dairy foods are not well understood. Contemporary attitudes and beliefs are likely influenced by high prevalence of lactose intolerance, as high as 90

– 100% amongst adults in some Aboriginal groups (Swagerty, Walling, Klein, 2002; Crowley, 1996) and lack of dairy products in the traditional Aboriginal diet.

Meat alternatives

With the meat-centric meals that many Aboriginal communities consume little is known about the acceptability of meat alternative-based meals (such as legumes, soy-based alternatives, nuts/seeds) or the addition of meat-alternatives to meals. Many meat alternatives are low glycemic index foods. Including low glycemic foods in a diabetic meal pattern has been shown to be beneficial for improved glycemic control and weight maintenance (Burani & Longo, 2006; Canadian Diabetes Association 2008).

Diabetes diet

Recommended healthy eating for diabetes, sometimes referred to as the Diabetes diet, has been described as undesirable; having symbolic connections to "medical power", the "white professional world", and distrust (Broussard, Bass & Jackson, 1982; Thompson et al., 2000). The "Diabetes diet" is felt to isolate the individual from their family/ community and disallowing full enjoyment of cultural feasts and social activities based around eating (Boston et al. 1997; Thompson et al., 2000).

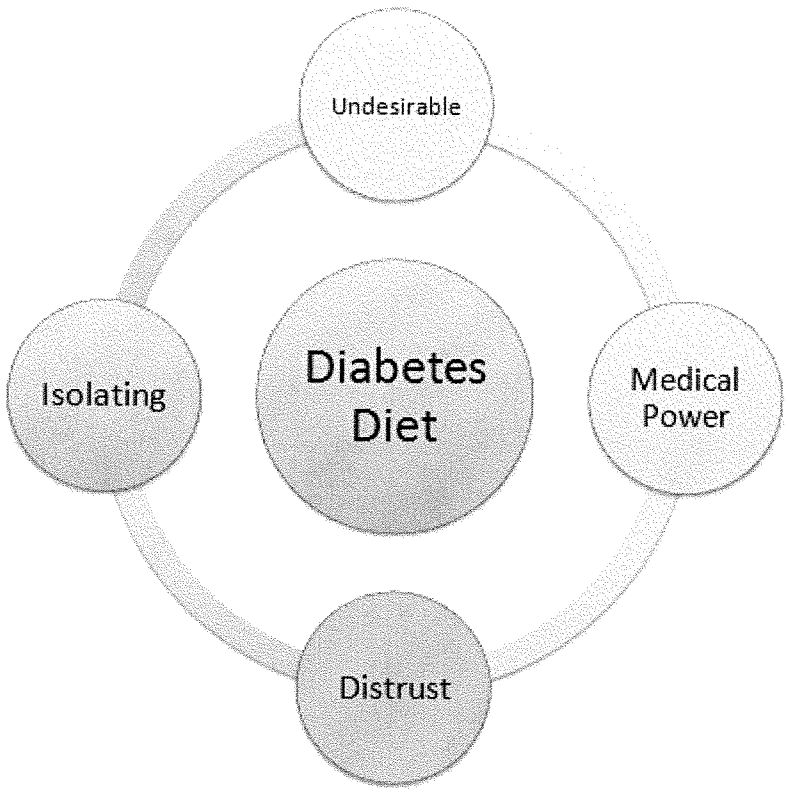

Figure 2.2: Aboriginal perceptions of the "Diabetes Diet" (Boston et al. 1997; Broussard, Bass & Jackson, 1982; Thompson et al., 2000).

It was suggested by Cree study participants that food considered to be "good" for diabetes was not considered to be "good" for Cree food beliefs and habits (Boston et al., 1997). In the Cree belief system animal fats were seen as "nourishing", "necessary", and "good" which was contrary to the diabetes education presented *(ibid.)*.

Beliefs and practice

More study is required of the relationship between individual beliefs and food intake (Willows, 2005). Taylor et al. (2006) found that health beliefs about food had little impact on consumption. Similarly, despite beliefs that traditional foods are important to optimal health low intake of traditional foods has been noted in a number of Aboriginal populations (Lytle et al., 2002; Talyor et al., 2006).

Improving our understanding of specific foods consumed and the role of beliefs and attitudes towards foods in selecting foods will allow for targeted nutrition education programming. Due to heterogeneity among Aboriginal populations there is a paucity of data on the beliefs and attitudes of Ojibwe with T2DM that would aid in this type of programming.

2.8 Family and Management of T2DM

The three major factors of the social environment that are known to affect self-care practices in patients with T2DM include the practitioner and health system, the community and work environment, and the patient's family (Auslander & Corn, 1996; as cited in Wen, Shepherd & Parchman, 2004). Since aspects of a patient's lifestyle, such as dietary management of diabetes, affect daily routines and family relationships, family can have an important effect on diabetes management (Choi, 2009).

Barton, Anderson & Thommasen (2004) found that amongst Aboriginal study participants it was felt that, "a diabetic life was intimately connected to family and the community" and concluded that there was a need for enhanced family and community connections to promote better outcomes for community members with diabetes. Despite this recognition that the familial environment is of great importance in relation to T2DM management the family has not been well studied in Aboriginal populations.

Family support in non-Aboriginal populations

Despite a lack of research in Aboriginal populations, research has explored the role of familial support in T2DM management in other minority populations. This literature may provide as a basis for theory in Aboriginal populations. However due to cultural differences in familial norms, practices and roles the utility of this research may be limited, though still informative.

Wen, Shepherd & Parchman (2004) found that amongst a sample of Mexican Americans higher levels of perceived family support and greater self-efficacy were associated with higher reported levels of diet and exercise self-care. The authors concluded that interventions designed to improve diabetes self-management should address family support specific to diabetes, self-efficacy, and barriers to self care (Wen et. al, 2004). Choi (2009) found similar positive associations, demonstrating that a higher level of dietary family support was significantly associated with lower A1C in Korean immigrants with T2DM. However, when gender was factored in family support was found to benefit men only and did not affect women at all or only at negligible levels (Choi, 2009).

Familial non-supportive behaviours in non-Aboriginal populations

While family has been established to improve diabetes dietary management and even show improvements in glycemic control in non-Aboriginal populations, Jones et al. (2008) found that family may also hinder diabetes dietary self-management and increase the difficulty of adhering to dietary guidelines. One participant described these challenges; *"I think the part that I am most disappointed about is my husband. I go to the store, and I do not buy the chips, the cookies, or the ice cream. However, when he goes to the store, he will buy the chips, the cookies, and the ice cream. They (husband and daughter) are like junk-food junkies ... I guess I want him to be more supportive in terms of what he buys and what he brings in the home ..."* (Jones et al.). Some participants felt that family members did not understand diabetes fully, so they were less inclined to adhere to certain household rules such as not bringing in sweet or "junk" foods into the house (Jones et al.).

Amongst a sample of immigrant Australian women, Kokanovic & Manderson (2006) found women experienced both supportive and non-supportive behaviours by family members. The women also distinguished between gaining support and receiving 'too much support'. The latter of which was perceived as intrusive and unwelcome. One participant described her difficulty with family support and diabetes management; "*Sometimes you know, with the family, that's why I don't want to share a lot because then they start getting in the action and doing things. They think it's their duty to do something or help. And that frustrates me.*" Because of how their health status affected family relationships, participants often felt alone with their illness; "*Even my close family or close friends do not understand what has happened to me in so short a time*

(complications due to diabetes) ... I think the only people who experience it (diabetes) can understand." (Kokanovic & Manderson, 2006).

Overview

The purpose of this study was to discover culturally shared local beliefs and attitudes towards foods that may impact the acceptance of dietary recommendations for the management of T2DM as outlined in national diabetes guidelines (American Diabetes Association, 2009; Canadian Diabetes Association, 2008). Of particular interest to the primary researcher was to explore the perceived relationship between traditional foods and T2DM, the influence of cultural gatherings and ceremonies on dietary self-management, and to explore family dynamics that influence the dietary management of T2DM. This interest in family dynamics emerged from experience the primary researcher had providing diabetes nutrition counseling to community members with T2DM in the role of a diabetes dietitian educator. Frequently in dietetic practice community members anecdotally described the strong influence family had on aspects of dietary management of their diabetes.

Chapter Three: Methodology

3.1 Study Design

Research design

A qualitative grounded theory research design was used in which focus groups were conducted to elicit data from Ojibwe (Anishinabek) community members with T2DM. Qualitative research is useful when exploring issues or problems of which little is known and/or a more detailed understanding is required (Creswell, 2007). Grounded theory is a inductive qualitative research approach in which the inquirer generates a general explanation, a theory, of a process, action, or interaction shaped by the views of a large numbers of participants (Strauss & Corbin, 1998; as cited in Creswell, 2007, p. 63). In this way the research is "grounded" in data rather than the literature due to the incomplete nature of research area being studied (Grounded Theory Institute, 2011).

In the current study this approach was chosen due to an incomplete understanding of food beliefs and attitudes towards many cultural issues that have implications for glycemic control. For example the impact of cultural ceremonies and events, and Aboriginal family dynamics on community members with T2DM is not well understood. Theories that model food beliefs and attitudes have been often developed with Aboriginal populations from varying geographical areas, historical and cultural influences which may not be applicable to local Aboriginal

communities. Locally conducted research with the population of interest is most useful in the development of future nutrition education strategies and programming.

Of the two major grounded theory approaches the constructivist approach was used in this study. Like the systematic approach to grounded theory the constructivist approach gathers rich qualitative data, codes raw data and uses theoretical sampling. However unlike the procedure–centric approach this approach emphasizes views, values, beliefs, assumptions and ideologies (Creswell, 2007). This approach relies on the researchers view, learning from experiences with networks, relationships, situations and making hierarchies of power visible (*ibid.*). Researcher reflexivity and flexible guidelines are used to capture the complexity of particular worlds and views. Despite being less systematic it remains rigorous leading to the emergence of conceptual categories. These concepts/categories are related to each other as a theoretical explanation of the action(s) that continually resolves the main concern of the participants in a substantive area (Grounded Theory Institute, 2011).

Due to the focus on cultural beliefs and attitudes and my own long-term immersion in this culture as a health care provider, the research design shares ethnographic characteristics. Ethnography is the study of an intact cultural or social group based primarily on observations and a prolonged period of time spent by the researcher in the field. The ethnographer listens and records the voices of informants with the intent of generating a cultural portrait (*ibid.*).This qualitative approach primarily uses observations and interviews for data collection, though other sources of data can be integrated into the study design as well. In this study I used interviewing, specifically focus group interviews, as the form of data collection. In particular, this study

explores the shared and learned patterns of attitudes, behaviors, and beliefs of a culture sharing group, Anishinabek with T2DM in M'Chigeeng First Nation, related to food.

3.2 Reflexivity

According to Primeau (2003) "... reflexive accounts are meant to demonstrate our awareness of our biographies, assumptions, and personal values, and to provide a context in which our analysis and interpretations can be understood. " Providing readers with information on the researcher's identity, credentials, occupation, experience and training increases the credibility of the research as it allows readers to assess the research results from a more informed position (Tong, Sainsbury & Craig, 2007). For this purpose I have provided my reflective thoughts pertaining to my role as a researcher in this study.

Most noteworthy is the dual role I served in the community during the study period. For five years I have worked in the capacity of a Registered Dietitian (R.D) providing nutrition counseling services for M'Chigeeng First Nation Health Services. This has allowed me to build a good rapport with health center staff and many community members. The second role I held in the community was that of community researcher representing Lakehead University for the present study. A significant portion of the research participants were familiar to me and fell within one of following categories; former or current patients in my role as an R.D, community members that have attended workshops that I have facilitated as an R.D, and individuals that I have worked with in the capacity as an R.D. This familiarity with me as an R.D working within the community led to some confusion as to what my role was during the focus groups. One

participant thought that I was providing some form of didactic information regarding diabetes at the focus group while yet another individual asked me direct knowledge based questions with the expectation that I would answer as "R.D." Several participants spoke of experiences with dietary counselling with two participants outwardly identifying myself as the R.D. To reduce the confusion of my dual roles within the community during the study period steps were taken to inform participants of my community researcher role;

1) *Letters of information* and *Letters of invitation* explicitly identified me as a primary researcher and graduate student with Lakehead University.
2) When providing personal invitations of participation over the telephone or in person I introduced myself as a graduate student researcher with Lakehead University. When potential participants queried about what this had to do with my role as a R.D. with Noojmowin Teg I informed them that the roles were separate and that participation or non-participation had no effect on the patient-provider relationship in anyway.

One of my personal concerns during the development of the study design was how my presence at the focus group sessions may affect open discussion. From the beginning it was clear to me that it would be inappropriate for me to conduct the focus groups for several reasons; one of which was the fact that my dual role in the community would likely hinder open and honest dialogue. Current or previous patients were the most at risk of being influenced by my presence during focus group sessions. I postulated that these individuals may not wish to make statements that would reveal non-adherence to agreed upon lifestyle goals and/or reveal poor attitudes toward healthy dietary recommendations. This reaction to my presence may be out of fear of

negatively affecting the patient-provider relationship or not wishing to receive professional disapproval. Some individuals may be prone to change their expressed commentary to seek professional approval from a current or past health care provider. These issues, possibly to a lesser extent, may also apply to individuals who are aware of my occupation as a Registered Dietitian and have a tendency towards approval seeking.

Although I felt that it was important to be present during focus group proceedings I wanted to minimize the effect of my presence during the discussions. Minimizing the potential negative effect of my presence would allow focus group discussions to unfold in a more open and honest manner. By physically creating distance between myself and the focus group participants and facilitator I felt that I could disengage myself from the group dynamics. For this effect the room was set up with the facilitator and focus group participants seated around a table as a closed group while I sat outside of this closed group 10 feet away seated quietly. My direct involvement was limited to reviewing the letters of information and providing guidance with the completion of the participant consent forms. Once these items were completed I removed myself from participation and the focus groups were exclusively facilitated by the facilitator.

During focus group discussions I found that my training as a Registered Dietitian and interest in leading a healthy lifestyle caused me to judge participants' expression of poor food beliefs, poor dietary practices or indifference to chronic disease management. Such comments caused a negative emotional response from me that I had to recognize to not allow it to color my interpretation as a researcher. Reflexivity allowed me to be aware of these biases and be aware of my personal values and beliefs as I proceeded with the research study.

3.3 Local research processes: Community-based participatory research

The Manitoulin Aboriginal Research Review Committee (MARRC) is a unique local community based ethics review committee that reviews health research proposals that involve First Nation communities within Manitoulin District. Since ethics is closely tied to culture the MARRC committee plays an important role of acknowledging and ensuring that First Nations values are represented in local research activities while adhering to national standards of ethics review (Noojmowin Teg, 2010).

The Research Review Committee evaluates research proposals on the basis of two interrelated guiding principles: ethics review and research review. Ethics review determines if a proposed research project respects Aboriginal customs and culture in the Manitoulin area. Research review determines if the research project follows the vision for culturally appropriate research on Manitoulin (Noojmowin Teg, 2010). These guiding principles are outlined within the Guidelines for Ethical Aboriginal Research (GEAR) document (Noojmowin Teg, 2003).

This local research review process encourages a style of research that follows Participatory Action Research (PAR) principles. Unlike basic research, PAR aims at both generating knowledge and producing action; and is driven by practical outcomes rather than theoretical understanding (Park, 1999). Additionally, research activities are based on the people's (e.g., clients, community members) role in setting the agendas, participating in the data gathering and analysis and controlling the use of the outcomes (Tandon as cited in Reason, 1998, p. 271).

The PAR methodology has gained support in Aboriginal communities where historical experiences with academic research have been poor. In March 2001, Noojmowin Teg Health Access Centre sponsored a community-based health research conference in M'Chigeeng First Nation to provide a forum for participants to discuss their experience with health research on Manitoulin Island. The following excerpt from the Noojmowin Teg website describes participant experiences;

> *Over the past years, First Nations communities within the District of Manitoulin Island were often contacted by academic researchers or other agencies to participate in health research projects. Despite these research activities many community agencies did not have access to relevant community health information to plan and develop community programs. At the community level, many people felt that their First Nations were being "researched to death"; however, there was no noticeable benefit to their community. Research activities were not designed to benefit the community and rarely led to action or change. Community agencies were also becoming increasingly concerned about the ethics of some of the research projects that were conducted locally, particularly the lack of community control over the research project.* (Noojmowin Teg, 2010).

A vital component of Participatory Action Research and the Guidelines for Ethical Aboriginal Research (GEAR) is involvement of community members and other local community stakeholders in the research process. GEAR recommends that the implementation of each research project be guided by a community-based steering committee. The function of this committee is to ensure that ethical values are upheld and that the expectations of the

organization, the community and the researcher are aligned (Noojmowin Teg 2003). Forming a steering committee allows communities to manage the day to day activities of the research project and respond to concerns in a timely fashion (Noojmowin Teg, 2003).

For the present study ethics approval was sought through two ethical approval processes; the Manitoulin Aboriginal Research Review Committee (MARRC) and the Lakehead University Research Ethics Board. Approval was initially sought through the MARRC committee. An ethics application was submitted to the MARRC committee on July 2009 and approval was granted September 2009. Lakehead University ethics application was submitted July 2009 and approval was granted October 2009.

3.4 Data Collection Procedures

Focus groups

Focus group methodology was chosen because of their usefulness for understanding cultural beliefs and issues about lifestyle (Blanchard, Rose, Taylor & Latchaw, 1999). Additionally, Krueger, Morgan, and Stewart & Shamdasani (as cited in Creswell, 2007, p. 113) state that focus groups are advantageous when individuals interviewed one-on-one may be hesitant to provide information. This may be the case when researchers are not from the study community and / or participants are shy. It was believed that an open and cooperative group setting would yield the best results.

Four focus groups lasting approximately 90 minutes each were facilitated by Alan Corbiere, a respected local Anishinabek community member. The focus group facilitator was fluent in the local Ojibwe (Anishinabemowin) dialect. The primary researcher observed, took field notes and operated the digital voice recorder, to ensure accurate transcription.

Sessions began with an explanation of the purpose of the focus group. A written consent form (See Appendix A) and letter of information (See Appendix B) were reviewed and completed, as well as permission to audiotape was obtained. Participation from all participants was encouraged. For transcription purposes participants were identified with codes. A code sheet was developed to balance quotes from a variety of individuals and allow for the removal of data provided by participants that chose to withdraw from the study.

Digital audio recordings were transcribed verbatim into Microsoft Word 2007. The primary researcher completed verbatim transcripts for two out of four focus group sessions. A transcriptionist was hired to review the completed transcripts for accuracy and complete the remaining transcriptions. The primary researcher completed spot checks on the transcripts to determine accuracy. Spot checks were completed by randomly selecting two pages of transcribed verbatim text per focus group and comparing these to the focus group audio recording for accuracy.

Focus group guide

The development of a focus group guide was guided and approved by the local research steering committee. The focus group guide was used by the local community researcher to facilitate discussion and provide probing questions and sub-questions. See Appendix C for focus group guide document.

Population sample

The purposive sample was composed of Anishinabek community members with T2DM in M'Chigeeng First Nation.

The following inclusion criteria were required for participant inclusion:

1) Reside in M'Chigeeng First Nation.
2) Over the age of 18 years.
3) Have been diagnosed with T2DM.
4) Of Anishinabek or other Aboriginal ancestry.

Participants were recruited with the help of flyers posted in the M'Chigeeng Health Center waiting area and by personal invitation by providers who were oriented to the purpose and goals of the study and to the participation criteria.

Sample size

Four focus groups were conducted with a total of twenty-two participants. One participant did not meet eligibility criteria and their data was removed from analysis, leaving a total of twenty-one focus group participants. This sample size was sufficient to reach a point of data saturation. Creswell (2007) recommends a sample size between 20 -30 individuals for ethnographic and grounded theory study to allow for a sufficient level of detail. The number of participants varied from 2-11 participants in each focus group.

Local Expert Advisors

Key informants composed of local expert advisors within M'Chigeeng First Nation or Anishinabek culture assisted with interpreting qualitative focus group data and help with *member checking* (See glossary). These included five individuals working with the local health services; 4 Aboriginal workers and one non-Aboriginal worker. Registered professions included Registered Dietitian and Diabetes Nurse Educator; non-registered staff included Traditional Medicine Coordinator, Lay Diabetes Educator, and a Community Wellness Worker. These local experts served to provide information regarding local tradition, traditional foods, customs and other aspects of Anishinabek culture that are not readily available from documented literature and not well described from focus group discussions. In addition these discussions were used to elucidate aspects of Anishinabek culture or local history that were not well known to the primary researcher. The elucidation of cultural aspects by local expert advisors, such as insight into Aboriginal family dynamics, was used for triangulation of the focus group data. This facilitated

the validation of data through cross verification from more sources to provide more credible data. The informal discussions with local expert advisors were not recorded verbatim and transcribed.

3.5 Data Analysis Procedures

Data was analyzed using qualitative thematic analysis. The primary researcher read the transcripts looking for salient categories, within categories, relational patterns and themes. As per grounded theory analysis and representation the researcher inductively developed codes across the focus groups and applied codes to all focus group transcripts (Creswell, 2007). Next, code families were developed to cluster similar codes and address the research questions (Creswell,). *NVivo 8*, a qualitative computer research software package (QSR International, 2010) was used to organize and code the focus group data. As more data was collected and analyzed, coding categories were refined. Transcripts with tentative coding and themes were provided to the local expert steering committee. The primary researcher validated the categories and themes with the local expert steering committee and reached consensus on the refinement of these parameters.

The development of thematic networks was used to further refine the thematic analysis. The lowest order themes were extracted from the transcribed focus group text, called basic themes. Categories of basic themes were grouped together to summarize more abstract principles (Organizing Themes). Organizing themes were further elevated to super-ordinate themes which

summarize the text as a whole (Global Themes). A summary of the three classes of themes can be seen in Table 3.1.

Theme of Level	Description
Basic theme	- Lowest-order theme that is derived from the textual data. - Are simple premises characteristic of the data, and on their own they say very little about the text as a whole.
Organizing theme	- Middle-order theme that organizes basic themes into clusters of similar issues. - More abstract and more revealing of what is going on in the texts. - Role is also to enhance the meaning and significance of a broader theme that unites several organizing themes.
Global theme	- Group sets of organizing themes that together present a position or an assertion about a given issue or reality. - They are macro themes that summarize and make sense of clusters of lower-order themes abstracted from and supported by the data. - Tell us what the texts as a whole are about within the context of a given analysis. They are both a summary of the main themes and a revealing interpretation of the texts.

Table 3.1: Levels of thematic analysis (Attride-Stirling, 2001)

The Thematic networks are then represented as web-like maps depicting the salient themes at each of the three levels, and illustrating the relationships between them (see Figure 3.1).

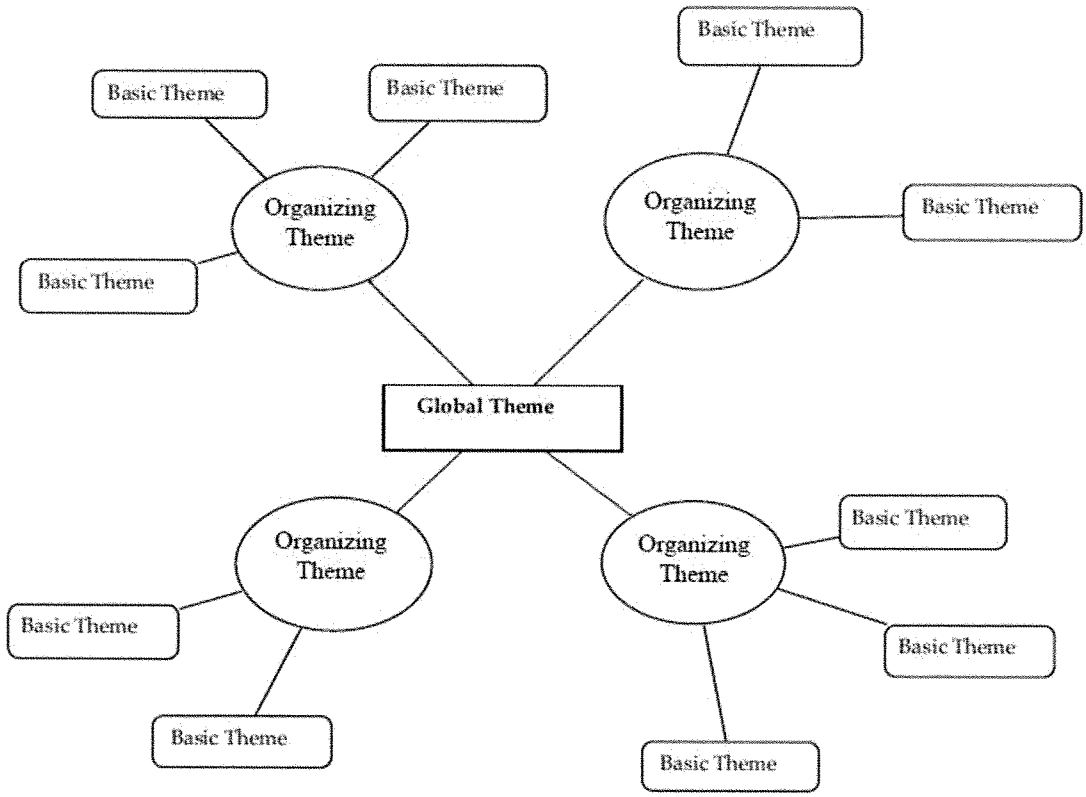

Figure 3.1: Structure of thematic network (Attride-Stirling, 2001)

Chapter Four: Results

4.1 Results

Overview

Focus group participants provided rich qualitative data that elucidated the perceived relationship between traditional foods and T2DM, the influence of cultural gatherings and ceremonies on dietary self-management, and to explore family dynamics that influence the dietary management of T2DM. The following section provides basic themes that emerged from the focus group discussions with community members with T2DM and key informants from M'Chigeeng First Nation.

Beliefs and attitudes about diabetes

Theme: Diabetes is a disease foreign to the Aboriginal community.

Diabetes within the community is conceptualized as a condition foreign to the Anishinabek people introduced by the white, European population; "*As far as the incidence of diabetes, (it) was not prevalent in the native population until the white settlers came over and brought their refined foods.*" (Participant Y.U).

Diabetes was described by one participant as a process that occurred post-contact with European settlers. An influence that caused a loss of balance with following the practices of the Medicine

Wheel; *" I'm going to go back a little bit to before the white man arrived. I'm going to go that far back. I keep hearing that you know how people ate at that time they were so healthy. They didn't have extra tires like I have today, you know .... Yeah and they were strong and built and they were handsome the guys ... not that the people aren't good looking now ... but they were strong. I would like to think they were balanced they followed the medicine wheel."*(Participant M.L.).

Theme: Diabetes causes a loss of control

Community members, when describing diabetes described a sense of loss in various aspects of their lives with the chronic disease. A loss of control over diet; *"You can't eat what you want"*, a loss of control over their health; *"It's going to kill you. You're going to die anyways. You might as well enjoy it while you're here"*; a loss of strength, *"All I think diabetes does is take the strength away"*; a loss of full participation in family meals and cultural events.

Theme: Diabetes causes a sense of fear

The most common emotion diabetes conjured for community members with diabetes was that of fear. Complications due to poorly managed diabetes were well known and visible in the community. One participant described her personal experience with diabetes in her immediate family; *"You know it was kind of scary because I watched my mom and other family members suffer through diabetes and it wasn't a nice thing to watch. See people losing their limbs and their eye sight. It was scary. Ok you got to snap out of it. This is not something you can play around with really. But again it's still hard because I'm addicted to pop so bad. It's kind of hard*

to get away from that." (Participant E.E.).

Although the complications due to diabetes were well known, how to manage the chronic condition was less well known by those without formal diabetes education; *"(I was diagnosed with diabetes in) Eighty-three (1983). I was scared what to eat, what not to eat, how much. How little. All that stuff. Should I eat this, or I shouldn't. I got all mixed up. How much tea should I drink, how much water, how much coffee, pop, chips and all that. I got all mixed up."*(Participant B.P.).

Community members newly diagnosed with diabetes or with pre-existing diabetes without the proper skill set to manage their blood glucose levels described greater levels of fear of diabetes and the secondary complications associated with poorly managed diabetes. Without the proper self-care strategies, including diabetes diet self-care strategies, combined with fear community members are likely to feel a lack of control over the chronic condition.

Diabetes and Food

Theme: Poor diet and food is the main cause of diabetes.

The predominant belief amongst community members with diabetes was that poor dietary choices is the major cause of diabetes; *"I think (food is the) the number one cause. Like what causes diabetes."* (Participant G.X.). An alternative view expressed was that food selection was a contributing factor to the appearance of diabetes but not the sole factor *"Maybe food plays a small part but I don't think it's all about food."* (Participant E.E.).

Theme: Milk shouldn't play a significant part in the Anishinabek diet, if at all.

Milk and dairy products were not consumed frequently by community members with diabetes. It was recognized by participants that historically milk and dairy products were not consumed in the traditional diet. It was believed that this lack of habituation to dairy products has caused the intolerance of dairy products amongst the Aboriginal people, as such many believed they were not an important part of a healthy diet. One participant's quote illustrates these beliefs; *"I think milk or cheese or any of that ... shouldn't play a big part of your diet anyway. You know for a lot of native people they're lactose intolerant ... I remember when my daughter was small and I took her to see a (traditional) healer for ... asthma ... and he told me to not to give her cow's milk, to give her soy milk if you had to give her milk ...So today my kids and me we don't eat a whole lot of dairy products."* (Participant E.E.).

Several participants took calcium pills due to not consuming adequate dairy while others consumed yogurt occasionally and/or cheese only from the milk and dairy group. *"I stay away from milk. I take alternatives ... Soya ... that fills the gap and I will not drink milk that's just for the little ones and it's for the little calves ... Little cows ... They talk about ...(how)... our bones ... need calcium but there are other ways to get that calcium."* (Participant M.L.).

Traditional foods and Diabetes

Theme: Heterogeneous opinions as to which foods categorized as traditional foods.

There were divergent opinions amongst diabetic community members as to what traditional foods consisted of and thus the utility of these foods in the management of T2DM.

One group identified historically gathered and hunted foods such as berries, fish and wild game as traditional. *"Our ancestors always had rabbit and deer. They didn't have ... cattle. (Nowadays we) ... are getting fed all kinds of cattle. We lived off the land. We ate deer, moose or whatever. I guess that would be our traditional foods. That would be better for us because ... they (the animals) weren't fed, they lived off the land. That was better for us, I guess."*(Participant R.K).

A second group of community members with diabetes believed that traditional foods included fried foods such as 'Indian tacos', fried scone, fried fish. *"Fried food, fat, that's what comes to mind, when I think of traditional foods ... everything that's supposed to be not good for you."* (Participant E.E.) , *"Traditional food to me is fat. That's all I eat. I eat everything fried. I barely bake."* (Participant B.P.).

A third group of community members did not consider items such as 'Indian tacos' and scone as traditional. This group believed that traditional foods included historically gathered and hunted foods but also included foods from their grand parents' generation. These foods included foods

such as fish pie, blood sausage, and head cheese. *"If anything is bad for you it's that goddamn Indian taco ... Tourists come into my place on Traditional Native night, Thursday nights, and we have fish pie, they say 'Do you have any Indian Tacos?' That's a Mexican dish that is not Native, I said. Natives didn't have flour."* (Participant Y.U.).

Theme: Traditional foods are healthy for people with diabetes as are the methods for gathering and preparing the foods.

The hunting and gathering of traditional foods was strongly connected to the past; both with ancestors and childhood memories, and a time when the Anishinabek people enjoyed optimal health. *"Our ancestors always had rabbit and deer. They didn't have you know like cattle ... we lived off the land ... that was better food for us I guess."* (Participant R.K.). The belief that traditional foods, particularly wild meats, were good for the Anishinabek people, as well as for the management of diabetes was emphasized;" *Oh I wish that I had some canned moose meat and canned deer I think that would help me a lot."*

The benefits of traditional foods went beyond the perceived health value of the foods. The connection to the past and to the land was viewed as important, *"It keeps you in touch too, eh, with nature. Out in the bush. Out and about there."*(Participant G.X.). Diabetic community members viewed the physical act of gathering and hunting for traditional foods as an additional benefit of traditional foods and as good for diabetes management. *"The other thing to like about traditional foods (is) the first thing you used to do is to gather it you know. So you were always walking you know, picking berries and hunting and all these things you know."*(Participant

G.X.), *"But you have to hunt for that stuff and that's exercise and I think that would help your sugars regulate I think, exercise."* (Participant S.C.).

Theme: The change from Traditional foods and lifestyle has caused the appearance and prevalence of diabetes in the First Nation communities.

Participants believed the change from a traditional lifestyle, which included a traditional food diet, to a contemporary lifestyle and diet caused the ill health amongst the Aboriginal population; *"Like you say with traditional medicine, like traditional foods. I mean that's why we are in the trouble we are in, we got away from traditional foods, eh.",*(Participant G.X.) ,*"(Traditional foods) ...that's what we grew up on. There was always fish, deer, rabbit, partridge in our fridge in our freezer. And then after that, I moved out of home and started to eat the laziest animals in the world, pig and cow. Look at me now, as big as a pig and as big as a cow. Now I have diabetes, when you mix the two that's what you get.*" (Participant F.Z.).

Theme: Community members wouldn't go back to a traditional way of eating.

Despite the belief that the loss of the traditional diet is related to the appearance of diabetes in the Aboriginal population diabetic community members with diabetes did not believe that community at large would revert to a traditional diet even if possible after being habituated to a western diet. Four reasons believed to restrict a reversion to a traditional diet included the time and labor intensive nature of traditional foods, changing taste preferences, a lack of natural

resources to sustain a community from an exclusive traditional food diet and environmental contamination of local food systems.

Traditional foods were described as time and labor intensive which ran contrary to the pace of contemporary life, in which people valued leisure time and quick ready-made foods. *"I listen to the Elders when they talk they say how it used to be but even they won't go back to the traditional methods ... nobody will go back to that because it was a lot of bloody work. Like that's too much work when you can be out playing bingo. A long, long day.", "(With traditional foods) probably you're spending more time making the food – you're not eating, you know? We have this big pot on the stove and I said ... 'Can you imagine they did this by hand before we have all this machinery... It would take them all day, she said to make it ... Even when they smoke the fish and stuff like that, you know, someone will have to tend the fire. Yeah but I think that ... right now everyone's in a hurry, everyone's in a hurry."* (Participant Y.U.).

Changing taste preferences were also cited as a barrier to a reversion to a traditional food based diet. Youth not exposed to traditional foods and those that have become accustomed to western foods were thought to not embrace a reversion to a traditional food based diet. *"I guess I don't know. It (traditional food) doesn't taste right anymore. I remember I used to eats lots (of traditional food). Even growing up we had fried liver cooked from the deer, deer heart. We used to eat a lot of that. I don't know how long ago, (I) had a deer heart and it didn't taste the same."*(Participant R.W.) Another participant stated, "*The old people are, they all said yeah I'd really like some of that now (traditional foods) but the young people it was an acquired taste. They don't want it, they say yuck! Uh I don't want that!"* (Participant Y.U.).

Despite the high health value placed on traditional foods by community members one participant noted additional challenges facing community members considering re-invigorating traditional eating *"...I don't know like you said that we can go back to that (traditional eating) because there's no fish ... and then the pollution eh, like how good is the traditional stuff anymore you know. But now they are talking about the mercury in all the fish and that people up north and we're getting sick with mercury ..."* (Participant G.X.).

Theme: The pattern of healthy eating for diabetes is restrictive and unappealing.

Community members with T2DM viewed the recommended pattern of eating for diabetes as restrictive; "*You get sick of some types of food (good for diabetes)*", (Participant D.E.), "*You can't eat what you want.*"(Participant S.C.) The foods believed to be good for diabetes were viewed as unappealing to participants and their families. "*Even those foods that are considered light and no fat and so far that food doesn't even taste good. I would rather eat the real thing and less. You know less. Eat the real thing.*" (Participant M.L.); *"In my family they are like 'yuck' (to diabetic recipes). Sometimes my kids are like 'Mom what is this?' But when they see me* saying *'I don't want to eat it either'. They're not going to eat it. It's hard man, it's hard.*" (Participant E.E.).

Several community members with diabetes found adhering to the diabetes diet difficult because of a self-described preference for high fat foods which ran contrary to recommendations by the advice by local diabetes educators and diabetes. This preference for fat, or *bimide* in the

Anishinaabe (Ojibwe) language, was described by one participant; *"Bimide is good, bimide is tasteful ... like anything with bimide tastes good. When you make gravy, like the real bimide is, when you make your gravy from the beef drippings or pork drippings, chicken drippings, you know, you add flour, make a roux and then you add some stock to that. bimide is tasteful ... (I've) always eaten the kind of food I have always eaten which is like fried scone, fried chicken, meat loaf. "* (Participant Y.U.).

Participants went on to describe how ingrained the preference for fatty foods was in some community members; "*My mom passed away six years ago and everything was related to her diabetes. Even when she was dying, in bed, we looked after her at home, she said "I don't want it, I don't want it" "You can't have fried fish" you know. So anyway I called the doctor one day he says, well the damage is done already let her eat whatever she wants to eat. But she didn't want that (poached) food, I said "Have some of this nice poached fish I made. She ate it when it was fried, but nothing like that. So we have a lot of beliefs and stuff like that that we gotta (sic) break."*(Participant Y.U.).

In contrast to fatty foods, vegetables were not a preferred food in the diet of community members with diabetes. While the majority of participants recognized vegetable consumption as an important part of a balanced diet several community members admitted to eating few vegetables, citing a lack of satiety from their consumption; "*You don't get full on them (vegetables)"* (Participant D.D), *"I know vegetables you can only eat them so long ... I hardly eat vegetables anyway. I like meat and fish."*(Participant V.M.).

Many community members with diabetes described a pattern of large portions and overeating prior to diagnosis of diabetes and continued difficulty controlling portions to manage blood glucose levels; *"... before I had diabetes ... I would sit down for dinner and I had my great big portions like that ... I think I had maybe 2 or 3 kinds of dessert, cake and pie and preserves. And I had the cake, pie and preserve stuff, it was real good. And I put the cake away and I said well I'm going to bed now."* (Participant V.M.).

Most community members recognized a need to cut down large portions though each individual had varying levels of success with this. A spouse of one community member in attendance stated that she had attempted to assist her diabetic husband with his portions and was met with great resistance; *"Nobody is portioning him to eat. One time I did that and he said 'You're killing me (with small portions)' and I said 'you're killing me (with large portions)' and I said 'we're killing each other'... There's no point in portioning what he eats"* (Participant M.I.).

Another community member with diabetes described her story of struggle with overeating and managing her diabetes upon diagnosis; *"(I thought) I have to look at the lifestyle. I knew I was gaining weight too much , that was a factor ... and my food intake I had to watch that. After a while I do get scared, you know, when I ate too much. I didn't like that feeling, that fullness. That's too much for me, you know and it scared me. I knew it was bad for me. I started portioning things, eating when I was supposed to as they directed. So I've learned quite a bit about the diabetes and all the experimenting. Like I can take things a different way and it's a matter of putting together. You know how do you piece this thing, how do you manage it, how*

does it work." (Participant S.E.).

Familial influences and upbringing were identified as shaping adult behaviours. One participant linked his pattern of overeating to the poverty he experienced as a child; *"Because we grew up poor and when you grow up poor you tend to gorge ... when we grew up we were not very rich and so you ate when there was lots money and you ate a lot ... I remember being very, very hungry too but you tend to overeat (when you can)."* (Participant Y.U.). Another participant described positive influences from family members to avoid overeating; "*My grandfather used to tell me when you eat you leave a little room, a little space there, so you're not too full, you don't want to sleep or something.*" (Participant M.L.).

Therefore the diabetes diet was viewed by community members as restrictive not only for restricting preferred foods and recommending less desirable food choices but also for prescribing smaller portions than individuals might have naturally consumed if it were not for diabetes.

Theme: Cultural events and ceremonies often do not provide a healthy food environment for community members with T2DM.

Participants described a lack of healthy options to choose from at the traditional pow wow *."...the pow wows have gotten 'fast food-icized' cause if anything is bad for you it's that god damn 'Indian taco' ... if you want a scone with the white flour, check your sugar after you have one piece of scone, Wooo! It goes right up ... you wouldn't be able to buy yourself a cup of cedar*

tea or something like that. We're looking at the real traditional native (food)... there is no more, there's no more."(Participant Y.U.). When describing the foods at the traditional Pow wow one participant stated "*Everything (is) drenched in oil. They all are. Yeah.*" (Participant K.T.).

Due to the poor food choices available at the traditional pow wow community members with diabetes described three types of strategies for diet self-care; 1) non-adherence to diabetes diet self-care, 2) partial participation, and 3) avoidance.

Many participants described non-adherence to their diabetes diet self-care by overeating or lack of portion control at pow wows. For some this caused poor glycemic control. *"I just eat everything when I go to pow wow."* (Participant L.I.), *"I would say at pow wow (my blood sugars are higher) because they have all these foods and you want to try everything. I know I do it ...Then when I get home I'm higher than a freaking kite (blood glucose levels). I got to down water and pace the floor ... But that's the only time it goes up high when I'm at a pow wow."* (Participant K.T.), *"I like the medication I get for my diabetes. If I go to a pow wow I say well I better take an extra pill. That's really, really good for me because I know how it is. I'm an excessive person."*(Participant V.M.).

According to community members the traditional pow wow does not provide a supportive environment for people trying to manage their diabetes. One participant stated that she limited her time at the pow wow due to her inability to self-manage at the event, *"This year I limited*

myself to staying at the pow wow because I knew I'd run into trouble (with my blood sugars). I said I'm going home now. I don't stay the whole full day." (Participant K.T).

Ceremonial fasts are an important traditional ceremony in the Anishinabek culture. Diabetic community members felt that they could not participate in a traditional fast. *"(As a diabetic) you wouldn't be able to fast"* (Participant K.T.), *"I don't think it's a good idea to fast because your sugar might drop. Some of them (healers) are very adamant about (only) having water there."*(Participant S.M.).

Some community members noted a movement towards a modified fast allowing people with diabetes to participate. This modified fast allowed community members to fast from solid foods while only consuming fluids such as vegetable juice and fruit juice every few hours to keep blood sugars safe and stable.

Some participants believed that the modified fast was not authentic, or as challenging as the traditional fast; *"I've been fasting even in my diabetes but I've been given just liquids but I don't think that's the real fasting."*(Participant M.L.); *"Well my fasting experience I was given liquids ... the fruit juice and the vegetable juice. It was o.k. you know every six hours or whatever they come and give you some juice. So I didn't find it really hard. If I had to go out and have absolutely nothing that probably would be quite scary for me."* (Participant E.E.). Despite these criticisms, it was felt that the modified fast was an important accommodation for community members with diabetes especially with this segment of the population representing a significant number of people within the community. One participant described this process of adaptation

and the benefits to those with diabetes "*But people (with diabetes) come out (from the fast) just glowing, healthier than the ones without diabetes ... so things are happening, so there are elders that are adjusting certain ceremonies for diabetics ... They're adapting.*" (Participant T.S.).

Community members felt that similar adaptations should be made at the traditional pow wow to accommodate the high prevalence of community members with diabetes. This was felt to allow community members with diabetes to become more fully engaged in the event and not have to choose between non-adherence, partial participation or avoidance of the event.

Community members felt that offering healthier choices at the pow wow would be one step to improving the environment for people with diabetes; *"It would be interesting to go to a pow wow and there's actually somebody who set up a diabetes, you know, food booth just for diabetics. Wouldn't that be killer?"* (Participant T.S.) One participant recommended offering boiled *giigoonh*, Anishaabemowin (Ojibwe) for 'fish', at a booth designed for people with diabetes. Another individual felt that an information booth for community members with diabetes would be beneficial for anyone having questions about managing their diabetes while at the event.

It was apparent from discussions with community members with diabetes that family has a great influence over food and meal choices available, ultimately affecting diabetes control. Family both provided behaviors that supported diabetes diet self-care and behaviors that were non-supporting.

Theme: Family supports behaviors of diet self-care

Family members supported individuals with diabetes in a variety of ways. The types of support provided ranged from information provision to meal preparation. Community members with diabetes who were not in the primary role of meal preparation described their family as being supportive by providing appropriate meals that allowed them to manage their diabetes. *"Oh, I think it's pretty good when I go to family because the majority of them are diabetic and they really take it serious. Sometimes you go and it's really bland and yucky. But you know that it is diabetic cook book (recipe) or whatever. So for me going to my family is pretty good because they are pretty good in taking care not cooking some stuff."* (Participant E.E.)

More commonly participants noted that family members would provide encouragement and information on what foods they should eat and closely monitored their intake. *"They all tell you 'Oh don't touch that. You're diabetic.'"* (Participant R.K.)

One participant noted that his family understood his needs for properly managing his diabetes and supported him by not having tempting foods around, *"My mother has diabetes and my brother has diabetes so when I go visit them we're eating pretty healthy. They eat good around me. When I'm not ... they're not (eating healthy), there's a lot of potatoes and pasta and fried stuff ... so I guess that people you're living with have to understand what your diabetes(is) and what you have to eat and how it affects you because I don't want to say 'Oh we can't have that. I shouldn't have that. But you guys can have it."*(Participant D.E.)

Although family provided supportive actions and behaviors at times, people with diabetes more frequently described non-supportive behaviors that family members engaged in that hindered diabetes diet self-care. Community members with diabetes who were not primarily responsible for meal preparation described a lack of control over having appropriate meals and foods available to manage their diabetes. One participant stated that, "*Same with at home. You're not going to quit eating because your wife made something different. She knows you're diabetic. What you're supposed to eat and what you're not supposed to eat. They know ... (the dietitian gave) me a paper like what you're supposed to eat, kind of have and not have and supposed to have. She usually doesn't follow that. Eat a little bit of this and a little bit of that.*" (Participant R.W.).

Community members with diabetes who had the primary role of meal preparation were not immune to having meals affected by family influences. Family preferences, attitudes and acceptance of meals limited the meals that the provider would prepare and thus the meals available to them to manage their own diabetes. *"In my family they are like 'yuck'. Sometimes my kids are like 'Mom what is this?' 'I eat it. It's good for you'. But when they see me saying, 'I don't want to eat it either', they're not going to eat it. It's hard man, it's hard."* (Participant E.E.).

Outside of regular meal times community members with T2DM discussed how they had conflicts over unhealthy foods and sweets that were brought into the house by the other family members. *"... My second oldest sister ... when she comes home she fills her trunk up with pop and chips and that. And I'm like "you're bringing that in here?" and then my dad (who has*

diabetes) sits there drinking and eating it while my mom (has it) now and then ... And they were wondering where the pop was going I was emptying it out in the toilet." (Participant K.T). The struggle that community members with T2DM had in trying to control the foods and meals available to them was a source of stress between community members and their spouses and other family members. This sense of conflict was described by one participant, "*And that's what happening in our house. We're fighting what we are going to eat, eh. If I can't eat that (I say) 'What are you trying to do kill me?' ... We are the opposite in what we want to eat, eh. I can't eat what he eats."*(Participant M.I.).

Another non-supporting behaviour that family members engaged in was that of excessive monitoring of food and dietary habits of their relatives with diabetes. It was generally believed that family members meant well, however participants found it intrusive, controlling and unwelcome. Community members with diabetes sometimes resisted attempts by family members to supervise their diabetes diet self-care as they sought to maintain control over their lives. One participant described ways that they circumvented intrusive dietary monitoring by family members, *"I'll go to the store and I'll say to myself, yeah darn right I'll get that can of Pepsi I'll drink it before I get home."*(Participant F.Z.). A mother and daughter pair both with diabetes described their struggle for control;*"When she (mother) goes to the grocery store she heads straight for the cake. And I'm taking them out. By the time she gets to the counter they are all back in. I'm like you can't have that. Now that I've got my own place she's got a whole stack of (unhealthy) stuff. I seen her."* (Participant K.T), (mother) "*I can eat what I want now."* (Participant D.D.).

Interestingly, the most common type of supportive and non-supportive behaviors described were that of information provision or monitoring. This form of behavior by family could be perceived as either supportive or non-supportive depending on the receptivity of the community members with diabetes. Other types of support were mentioned less frequently.

Theme: Feelings of being isolated because of diabetes within the family.

Community members with diabetes described feelings of isolation and exclusion in their family due to having to follow diabetes dietary guidelines for self-management. This increased the difficulty of adhering to a healthy eating pattern and ultimately to optimal blood glucose control. One participant described her feelings of isolation and her eventual relapse to an unhealthy eating pattern, "*Yeah. (My attitude) ... was 'eat whatever I want to eat. I couldn't control it anyways'. Seeing everybody in my family eating, eh. They eat normal except me. I was just diabetic the first one in my family. So they ate whatever they wanted to eat. So I just enjoyed it too. I just jumped into what they ate. So why should I hold back when everybody else is enjoying their food.*"(Participant B.P.).

Theme: The desire to not be a burden to family members they were visiting with the dietary needs.

Community members with diabetes described not wanting to be a burden to family members when sharing meals. They were reluctant to impose their personal dietary guidelines upon family they were visiting that were providing food; *"... I'm not going to be there very long. I'll just say*

(to my relatives) when I go home I'll cook my own stuff the right way. I'm not going to bother yous (sic) to make it right for me. ... I'm going to eat that'll help me to get by but when I get home I'll cook my own. But I wouldn't put them down for it I'd say 'That's ok I'll just pick what's supposed to be good for me out of what you cooked. I'm not going to bother yous (sic) because I'm a diabetic.'"(Participant R.K). Another participant expressed similar sentiments; *"... I don't tell them that, 'No this stuff is not good for you.' Or get them mad at you because they cook. They took all day to prepare a meal you coming over ... You take a little bit maybe just say 'You had something' and they know that you're diabetic ... They just cook what they want. What are you going to do. I'm not going over there because you don't cook because I'm a diabetic."*(Participant R.W).

Theme: Self-management is vital when visiting family

Community members with diabetes described self-responsibility as an important factor in managing diabetes while visiting relatives. One participant summed up the responsibility of the individual with diabetes, *"I have to look after myself at the table."(*Participant V.M.). One participant felt that, *"You have to pretty well take your own stuff,"* (Participant G.X) in order to manage your diabetes during a family visit. A community member who does just that found that this was met with resistance; "I *carry a kit (food) bag. Even for my son, eh. (My relatives) said, 'Holy cow we have lots of food.' I said 'Not the kind I eat. You got all junk food.' They get offended when (I) bring my food."* (Participant K.T.).

Participants who were less pro-active adapting the food environment to meet their dietary guidelines when visiting relatives expressed a willingness to make the best of the meal and food choices available to them. Strategies included avoidance of poor dietary choices or choosing only small portions. *"You stay away from the desserts, you know. Instead of eat a big portion of potatoes you just have watch what you eat."* (Participant G.X.).

Participants recognized that family members with or without diabetes were not always role models for the dietary management of diabetes; *"It makes you wonder; you look (at) what some family members what they do. They're ... almost like they're wanting to commit suicide with diabetes. You go to someone's place and you see them with amputations and they got a can of Pepsi or a whole box of Pepsi sitting by their side and then a bag of chips."* (Participant G.X.). Several participants found it difficult to follow dietary guidelines while in the company of family. "*You could if you wanted to I guess, but you always say 'I'm going to have some of that and some of this', you know. No use in lying.*" (Participant R.W.) *"... Seeing everybody in my family eating, eh. They eat normal except me. I was just diabetic, the first one in my family. So they ate whatever they wanted to eat ... So I just enjoyed (their food) too. I just jumped into what they ate. So why should I hold back when everybody else is enjoying their food."*(Participant B.P.).

Summary

Community members with T2DM conceptualized diabetes as a disease foreign to the Aboriginal population. Diabetes caused fear and a sense of loss of control over many aspects of life; including health, food choices and full participation in family meals.

A poor quality diet was believed to be the main cause of diabetes. More specifically some community members with T2DM believed that the change from a traditional foods-based diet and traditional lifestyle caused the appearance and high prevalence of diabetes in the First Nation communities. Not only were traditional foods believed to be healthy for people with diabetes but the methods for gathering and preparing the foods were also viewed as being beneficial for diabetes control. Despite the positive beliefs in the power of traditional living and foods community members with T2DM believed that the community at large would not go back to a traditional way of eating due to a variety of factors. These included; changing taste preferences, the labor intensive nature of traditional food hunting/preparation, lack of natural food resources, and the environmental contamination of local food systems.

An Aboriginal view of health includes a holistic perspective that recognizes a balance between the four components of health; the physical, emotional, mental and spiritual (Conti, 2006). Cultural ceremonies and events play an important role in supporting health in several of those components of health. For example, traditional dancers at a pow wow benefit from the physical exertion of prolonged dancing (physical health), the positive effect of releasing stress from interacting with fellow community and family members (emotional health) as well as the benefit from expressing Anishinabek cultural identity through celebration and ceremony (spiritual health). However, participants stated that the traditional pow wow in its present form does not provide a healthy food environment for those trying to manage their diabetes. Ceremonial fasts were found to be more supportive with contemporary adjustments to accommodate community

members with diabetes who wished to still participate. However these modified fasts were less well known and possibly under-utilized for this reason by diabetics.

Family, an integral component of self-care (Choi 2009; Fisher, Chesla, Bartz, Gilliss, Skaff & Faa, 1998; Jones et al, 2008; Wen, Shepherd & Parchman, 2004), was believed to both provide support and hinder diabetes diet self-care. Without family support some participants had feelings of being isolated within the family unit because of diabetes and felt that they could not participate in regular family meals. When visiting family members outside of the household there was a strong desire to not burden family members because of their perceived special dietary needs. However when trying to engage in diabetes diet self-care at relative's homes there was the risk of breaking cultural norms by following dietary recommendations for T2DM. Community members with diabetes felt that self-management was vital when visiting family and the sole responsibility was on the individual with diabetes rather than the hosting household providing the meals.

5.1 Discussion

Organizing theme: Diabetes as terror

Diabetes was seen as a terror to the community and to individuals with diabetes. It was described as a foreign disease, causing a great sense of fear amongst non-diabetics and community members with diabetes alike. The word 'Terror', defined as extreme fear (Oxford dictionary, 2011) aptly describes quotes from participants regarding their view of diabetes in the community. One participant described the fear she had as she saw her health slowly deteriorating from the effects of poor glycemic control, "... *it's scary. I'm only 39 years old and ... my vision is (already) impaired because of diabetes. That's bad. They say people don't get cataracts in their eyes until 60s, like (in their) later years. Here I am at 39. It's no good. I've (also) got nerve damage. It's crazy.*" (Participant E.E.). The terror felt in the community was often fuelled by the examples of advanced complications and deteriorating health secondary to diabetes. Most community members with diabetes had examples of relatives or friends that had experienced complications associated with diabetes. *"Like I got two brothers who are in really, really bad shape and they don't watch their diet. ... they never ever tried to calm any of their (behaviours) ... (Now they are on) Dialysis, (have) amputations and stuff like that.* " (Participant Y.U.).

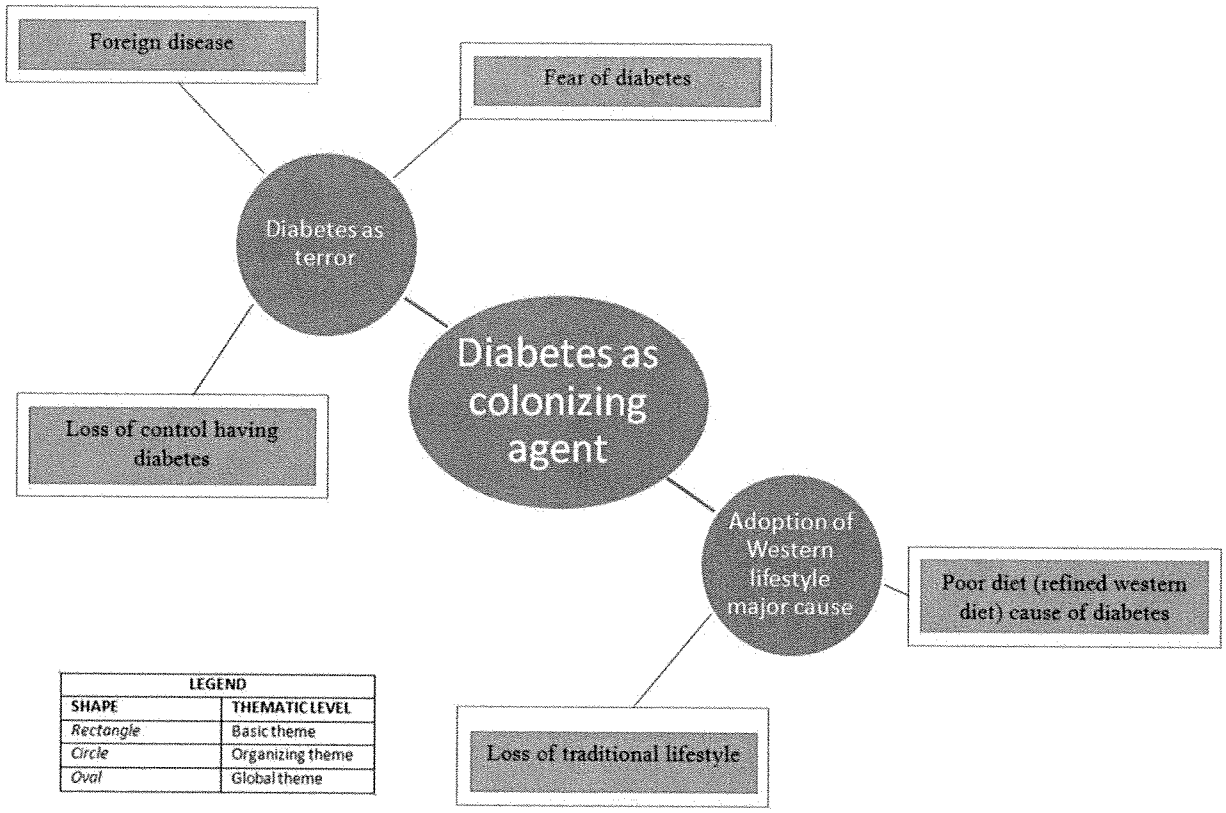

Figure 5.1: Thematic map for "Diabetes as colonizing agent"

Basic Theme: Diabetes is a disease foreign to the Aboriginal community.

Diabetes was not seen as a disease coming from within the community but from outside of the community and outside of the Aboriginal world. Diabetes was attributed to foreign influences; specifically the white, European population. One community member summarized the general sentiment; "*As far as the incidence of diabetes, (it) was not prevalent in the native population until the white settlers came over and brought their refined foods.*" (Participant Y.U)

These beliefs are similar to findings described by other authors exploring the cultural

understandings of diabetes for First Nation peoples. Boston et al. (1997) found that the Cree believe that the cause of diabetes to be the 'white man' whose presence has influenced the Cree lifestyle negatively causing the spread of diabetes and a decrease in the 'bush life' which was protective to Cree wellbeing. In one Anishinabek community participants described diabetes as a new disease related to broader social and environmental changes post-colonization and the accompanying dietary changes (Garro, 1995).

Basic Theme: Diabetes causes a loss of control

Community members described a sense of loss in various aspects of their lives once the diagnosis of diabetes was made. Prior to diagnosis individuals were able to engage in unrestricted diet and lifestyle choices, fully engage in cultural events and social activities without thought of how it might affect their overall health status. Now with the diagnosis of diabetes participants were burdened with guidelines and recommendations by health professionals, friends and family that did not always fall in line with their natural approaches to lifestyle choices. Hence many community members felt like their autonomy was taken away by the diagnosis of diabetes and the maintenance of glycemic control. Community members described the limitations placed upon them; *"You can't eat what you want"* (Participant S.M.), and the difficulty with accepting external guidelines in directing their lifestyle and dietary decision making; "*So now I'm trying so hard to know what's good and what's not. It's very hard. Especially when you're used to eating whatever it is you want to eat whenever you want to eat it.*" (Participant E.E.).

This perceived loss of control over various aspects of life indicates a shift towards an external locus of control. This finding is similar to that found by Jones et al. (2008) where a loss of control was described by a group of African American women diagnosed with T2DM. This may be problematic for diabetes control as research demonstrates that self-care behaviors, including dietary adherence, is affected by one's appraisal of control. Macrodimitris and Endler (2001) found that an individuals' appraisal of his or her chronic condition as controllable or uncontrollable influenced choice of coping strategy. The predominant coping strategies used by individuals appraising their condition as uncontrollable included avoidance and emotional-focused coping (Macrodimitris & Endler, 2001). Avoidance is a type of coping that "*serves as a form of escape from the unpleasant stressful situation*" and does nothing to manage the chronic condition (Parker & Endler, 1992, as cited in Macrodimitris & Endler, 2001). Emotion-focused coping involves regulating the emotion and distress associated with the stressor (Macrodimitris & Endler, 2001). There are many such coping strategies, most of which involve cognitive processes directed at lessening emotional distress. These strategies include minimization, distancing, and finding positive value in negative events (Grey, 2000).

While avoidance and emotion-focused coping are useful when nothing can be done to modify the event or stressor (uncontrollable), or when the stressor is transitory and will resolve itself (Grey, 2000) it, however, is not a constructive coping strategy with a controllable disease such as diabetes. Avoiding the integration of positive lifestyle and dietary changes or ignoring poor blood glucose control can increase the risk of developing or progressing existing complications. While emotion-focused coping is important in moderating emotional stress, which can be contributor to hyperglycemia, this coping strategy does not address recommended positive

lifestyle management, blood glucose monitoring or medication that contribute to blood glucose control.

Individuals perceiving their chronic condition as controllable are more likely to engage in problem focused coping strategies (Macrodimitris & Endler, 2001). Problem-focused coping is aimed at solving the problem that faces the person and is most likely to be used when the stressor is perceived by the individual as controllable (Grey, 2000). For a person with diabetes, problem-focused coping strategies may be used in managing difficult eating situations. In general, problem-focused coping strategies are associated with more successful medical outcomes than emotion-focused ones. Problem-oriented coping strategies have been associated with better self-care, metabolic control, and psychosocial well-being in adults (Grey, 2000). Therefore one's perception of control may be an important factor in whether or not actual glycemic control is maintained (Macrodimitris & Endler, 2001).

The goal of diabetes education as a whole has been to promote certain lifestyle behaviors in the person with diabetes that will result in better choices, better health, and fewer complications (Krichbaum, Aarestad & Buethe, 2003). In traditional diabetes nutrition education, diabetes educators have assumed that persons with diabetes believe that the chronic disease is controllable and that dietary management is efficacious. This assumption leads to the Educator to teach a curriculum that promotes diabetes self- management, This may include basic diabetes patho-physiology, national or local food guides, carbohydrate containing foods, plate portion method, carbohydrate budgeting, carbohydrate counting, handling difficult eating situations during celebrations or restaurants. This nutrition education orientation emphasizes knowledge

acquisition and attempts to progress the individual towards incorporating problem-focused coping strategies. This nutrition education orientation works well for individuals who perceive diabetes as controllable; however it may be a mismatch with individuals who perceive diabetes as uncontrollable. Individuals that believe that their diabetes is uncontrollable were unlikely to follow diabetes nutrition management strategies;" *(I) eat whatever I want to eat. I couldn't control it anyways. Seeing everybody in my family eating, eh. They eat normal except me. I was just diabetic the first one in my family. So they ate whatever they wanted to eat. So I just enjoyed it too.*" (Participant B.P.).

A lack of perceived control with diabetes suggests a shift in locus of control upon diagnosis of diabetes or somewhere along the time line of perceived "futile" self-management. This shift in locus of control could lead to hopelessness and fatalism in the face of diabetes, as evidenced by one participant's description; *"It's going to kill you. You're going to die anyways. You might as well enjoy it (food) while you're here."* (Participant D.D.).

Similar findings were reported by Lautenschlager and Smith (2006) who found fatalistic attitude towards diabetes prevented some from actively managing their diet. A few participants had attempted to use diet to control their disease, but they did not see the use in continuing the dietary regimen when it did not produce favourable results. One of the participants explained, "*It really don't matter what I eat ... because my sugars will always, whatever I eat ... my sugars rise ... so I eat whatever I want.*" (Lautenschlager & Smith, 2006).

Surgenor, Horn, Hudson, Lunt and Tennent (2000) found that participants with optimal HbA1C status had significantly higher levels of overall sense of control than those with either suboptimal control or poor HbA1C status. Therefore the researchers concluded that a heightened overall sense of control is associated with improved diabetes control, while a sense of passivity and helplessness is detrimental to diabetes control. Related findings were demonstrated by Aljasem, Peyrot, Wissow and Rubin (2001) who found that greater self-efficacy predicted more frequent blood testing, less frequent binge eating and closer adherence to an ideal diet. Self-efficacy was especially important when the challenge to be faced is more difficult.

There has been a realization in the research community and health education sector that knowledge alone is an insufficient predictor of a person's capabilities to incorporate new self-care behaviours of diabetes management into their daily activities (Booker, Morris & Johnson, 2008; Krichbaum, Aarestad & Buethe, 2003).

Booker, Morris and Johnson (2008) found that through the acquisition of trustworthy information and a repertoire of coping skills accompanied by regular contact with other people with Type 1 Diabetes participants achieved an increased sense of control in their lives and were empowered to change. In comparison to a matched sample of patients receiving normal clinical care, the intervention group showed significantly lower HbA1c level post-intervention (Booker, Morris & Johnson, 2008). Similarly, Rubin, Peyrot & Saudek (1993) found that an intensive diabetes education program improved diabetes-related attitudes and measures of emotional well- including diabetes self-efficacy, which is closely linked to diabetes self-management behaviors.

In practical terms, identifying an individual's current locus of control and level of self-efficacy in relation to their perceived ability to live successfully with diabetes may be beneficial. Individuals with lower identified levels of self-efficacy and an external locus of control may be at higher risk of poor diabetes control.

In light of these research findings, diabetes educators and diabetes education centers should consider providing people with positive control experiences that provide them with opportunities to increase their sense of control and self-efficacy thus increasing the likelihood of better diabetes control. To attain this goal education sessions need to involve fewer lectures and more practical interactive exercises that focus on developing specific skills (Krichbaum, Aarestad & Buethe, 2003). From a dietary standpoint this could include an increased focus on improving diabetes cooking skills, label reading, menu planning, using self monitoring of blood glucose (SMBG) to adjust dietary intake and/or insulin. This would require a conscious effort to break the assumption that all individuals have an internal locus of control and high self-efficacy.

The inequalities observed in the social determinants of health of Aboriginal people, in the realms of income, education, employment status and working conditions, early childhood development, food insecurity, housing, and the continued effects of colonization may make the task of increasing self-efficacy and promoting an internal locus of control more difficult in this population. Furthermore, a lower level of self-efficacy may be expected in individuals experiencing inequality in the social determinants of health. However, the development of specific diabetes self-care activities in the area of dietary self- management; such as label reading, carbohydrate counting, self-monitoring of blood glucose and others,

may encourage a shift in locus of control if individuals experience positive self-learning opportunities and observe success in positively affecting their blood glucose levels.

In addition, further effort would need to go into shifting efforts of Diabetes Educators from being predominantly purveyors of knowledge to educating people with diabetes is to improve their individual self-efficacy and accordingly self management ability (Krichbaum, Aarestad & Buethe, 2003). This may require diabetes education services beyond the scope of practice of core diabetes education staff (i.e. Diabetes Nurse Educator, Diabetes Dietitian Educator) and require support from other supportive health professionals (mental health, traditional health, etc.).

Basic Theme: Diabetes causes a sense of fear

The most common emotion diabetes conjured for community members with diabetes was that of fear. Complications due to poorly managed diabetes were well known and visible in the community. Without the proper skill set to manage their blood glucose levels, greater levels of fear of diabetes and the associated secondary complications were described.

Factors described by community members with diabetes that contributed to fear included; a generalized fear within the community of diabetes, having peers or relatives with advanced secondary complications or death due to poorly managed diabetes, a sense of loss of control over health due to diagnosis of diabetes, an inability to control blood glucose levels, the appearance of the secondary complications of diabetes and a lack of diabetes education (see Figure 5.2).

Figure 5.2: Contributing factors to fear of community members with diabetes

The proposed contributing factors include both modifiable and non-modifiable factors (see Table 5.1).

Modifiable factors	Non-modifiable factors
• Lack of diabetes education	• Peers with advanced complications and death due to diabetes
• Inability to control blood sugars	• Community attitude towards diabetes
• Sense of loss of control	• Appearance of secondary complications of diabetes

Table 5.1: Modifiable and non-modifiable factors contributing to fear of diabetes at the individual level.

Without the proper self-care strategies, including diabetes diet self-care strategies, a lack of control over the chronic condition was described as contributing to the experienced fear; *"(I was diagnosed with diabetes in) Eighty-three (1983). I was scared what to eat, what not to eat, how much. How little. All that stuff. Should I eat this, or I shouldn't. I got all mixed up. How tea should I drink, how much water, how much coffee, pop, chips and all that. I got all mixed up."* (Participant B.P.) As previously noted a lack of control, or external locus of control, has been associated with poor glycemic control in study participants (Aljasem, Peyrot, Wissow & Rubin, 2001; Surgenor, Horn, Hudson, Lunt & Tennent, 2000). Therefore it is reasonable to conclude that community members with diabetes would benefit from diabetes services or program, such as diabetes self-management classes, that targeted these modifiable factors to reduce the fear associated with diabetes to promote improved blood glucose control. Those requiring more intensive supports may benefit from referral to mental health services.

Organizing theme: Adoption of western lifestyle major cause of diabetes

This organizing theme pertains to the belief that the adoption of a western lifestyle, with the associated refined foods and sedentary lifestyle caused the appearance of the diabetes in the Anishinabek nation (See Figure 5.1). Concurrently a loss of the traditional way of life occurred. The traditional diet was described as protective of Anishnabek health and necessary for optimal health for Anishinabek community members.

Basic Theme: Poor diet (western refined foods) main cause of diabetes.

The predominant belief amongst community members with diabetes was that poor dietary choices, specifically western refined foods, were the major cause of diabetes in the community; *"I think (food is the) the number one cause. Like what causes diabetes."* (Participant G.X.). An alternative view expressed was that food selection was a contributing factor to the appearance of diabetes but not the sole factor *"Maybe food plays a small part but I don't think it's all about food."* (Participant E.E.) This is similar to findings by Lautenschlager & Smith (2006) where participants identified diet, lack of exercise and being overweight as the cause of diabetes. With respect to diet, particularly frequently thought overeating or eating the wrong types of foods was responsible for the onset of diabetes. Some identified "unhealthy food" and "fatty foods" as being responsible for the diabetes epidemic, but others felt that specific foods, such as alcohol, fat, fat foods, and pop caused the disease. (Lautenschlager & Smith, 2006). Harnack, Story, Rock, Neumark-Sztainer, Jeffrey & French (1999) reported that amongst a group (n=219) of Lakota adults in South Dakota 86.3% believed that diabetes was related to dietary behavior.

In contrast to western foods, traditional foods were described as healthy for Anishinabek community members with diabetes for their high nutritional value. A high health value ascribed to traditional foods, particularly to wild meats, has been noted in other Aboriginal health research (Boston et al., 1997; Gittelsohn et al., 1996; Wein, 1996; Wein, Sabry & Evers, 1989). The connection between good health and traditional foods went beyond mere nutritional value. The act of hunting, gathering and trapping of traditional foods was strongly connected to the past; both with ancestors and childhood memories. This promotes spiritual health from the strong cultural connection that is important for Anishinabek self-identity. A high level of spiritual health would likely be beneficial in managing the stresses of chronic disease management. Maar, Manitowabi, Gzik, McGregor & Corbiere (2011) found that traditional spirituality was often discussed as beneficial to the overall well-being of patients with diabetes.

A further benefit of traditional foods described was the physical act of gathering and hunting. One participant described this benefit; "*... you have to hunt for ... (wild game) ... and that's exercise and I think that would help your sugars regulate I think, exercise.*"(Participant S.M.). During and after all but the most intense exercise, blood glucose tends to decline due to increased glucose disposal and insulin sensitivity (Canadian Diabetes Association, 2008). Beyond this short term control, moderate to high levels of physical activity and cardio-respiratory fitness are associated with substantial reductions in morbidity and mortality in both men and women with T2DM (Canadian Diabetes Association).

Basic Theme: The belief that the change from Traditional foods and lifestyle has caused the appearance and prevalence of diabetes in the First Nation communities.

Participants believed the change from a traditional lifestyle, which included a traditional food diet, to a contemporary lifestyle and diet caused the ill health amongst the Aboriginal population. The disruption of traditional food systems of First Nations peoples and the transition from a traditional diet to a predominately western food-based diet has gained considerable support as a major contributor to the appearance and dramatic rise in T2DM (Batal, Gray-Donald, Kuhnlein & Receveur, 2005; Compher, 2006; Conti, 2006; Sunday, Elyes, Upshur, 2001). Sunday, Eyles and Upshur found that Anishinabek in Whitefish River First Nation, only 47 kilometres from M'Chigeeng First Nation, a significant number of community members named dietary change as a causative factor in the epidemic of diabetes in the community. However, the emphasis placed on dietary change as a cause of diabetes was less than the emphasis placed on genetics. Interestingly, none of the participants in the current study mentioned genetics as a risk factor or causative factor for the development of T2DM.

Despite the belief that the loss of the traditional diet is related to the appearance of diabetes in the Aboriginal population diabetic community members with diabetes did not believe that community at large would revert to a traditional diet even if possible after being habituated to a western diet. Four reasons believed to restrict a reversion to a traditional diet included the time and labor intensive nature of traditional foods, changing taste preferences, a lack of natural resources to sustain a community from an exclusive traditional food diet and environmental contamination of local food systems.

Traditional foods were described as time and labor intensive which ran contrary to the pace of contemporary life, in which people valued leisure time and quick ready-made foods. Changing taste preferences were also cited as a barrier to a reversion to a traditional food based diet. Youth not exposed to traditional foods and those that have become accustomed to western foods were thought to not embrace a reversion to a traditional food based diet. This preference for traditional foods by older age groups has been noted in other communities (Bersmin, Luick, Ruppert, Stern & Zidenberg-Cherr, 2006; Kuhnlein, Receveur, Soueida & Egeland; 2004; Wilson 2005). This is likely due to greater historical availability of traditional foods, less availability of market foods and a familiarity with traditional foods during childhood.

The promotion of traditional foods is an important approach to improving the overall diets of community members with diabetes. Diets composed of traditional foods have been found to have higher levels of nutrients than those without traditional foods (Kuhnlein, Receveur, Soueida & Egeland, 2004; Wein, 1996). M'Chigeeng First Nation has already supported community-wide cultural initiatives in 2010 and 2011 to promote traditional foods. These events have increased awareness, knowledge and skills of community members (Crystal Morra, Noojmowin Teg Aboriginal Health Center Community Dietitian, personal communication, January 24th 2011).

Global theme: Diabetes as colonizing agent

Two organizing themes emerged from the focus group data in this thematic network; 1) diabetes as terror and 2) adoption of a western lifestyle is the major cause of diabetes. These two themes

pointed towards a conflict between the Anishinabek traditional lifestyle and Western lifestyle, which emerged as central within this network (See Figure 5.1).

Research into the fundamental causes of poor health among Aboriginal Canadians points to varied determinants of health (Cheadle et al., 1994; Mikkonen & Raphael, 2010; Richmond, 2007; Richmond & Ross, 2009). Most recently, post-colonial influences have become recognized as a major contributor to the poor health status of the Aboriginal population (Richmond, 2007; Richmond & Ross, 2009).

The construct of colonization can be extended to the introduction and presence of diabetes in the Aboriginal world. Conceptualized as a foreign disease resulting from the forced adoption of a predominately refined western diet; diabetes may be viewed as an agent of colonization, oppressing Anishinabek health.

Although a historical analysis of colonization is beyond the scope of this thesis, a brief synopsis is appropriate. Prior to Western contact Aboriginal peoples subsisted off of the land; hunting, gathering, fishing and trapping to provide for their nourishment (Kuhnlein, Receveur & Chan, 2001; Willows, 2005). From the time of European contact the Aboriginal people sustained a gradual loss of traditional lands, plants, animals, fish, and traditional water sources to the new settlers and governments. The Indian Department established circa 1755, a government ministry in British North America, negotiated numerous treaties with the Aboriginal tribes in the Great Lakes Basin and St Lawrence River area over the following half century (Leslie, 2006). Amongst its actions the department negotiated the surrender of lands and resources, and the establishment

of reserves for specific communities (Leslie). Due to limited land on reserves Aboriginal people were limited in their access to traditional food resources and could no longer rely on traditional food sources to provide enough nutrition to support health. This caused a reliance on non-traditional food sources and an ever increasing dependence on market foods. The government at the time began providing monthly food packages, called "government rations" that consisted primarily of coffee, sugar, flour, cereal, rice, beans, beef and salt pork (Conti, 2006; Marjory Shawanda, personal communication, March 15th 2010).

As a result of government oppression and significant reductions in land available for hunting, gathering and fishing Aboriginal people were forced to transition from a traditional food based diet to a predominantly market food-based diet. This necessitated a shift from a traditional economy to a market based economy. Participation in a market-based economy requires currency for participation. As described earlier, the inequalities in the social determinants of health, particularly in the areas of: income and income distribution, education, employment / unemployment and job security, put many Aboriginal people at a disadvantage in a market-based economy. Community members with diabetes described the difficulty in procuring the healthiest foods in this type of economy, *"... the other cuts (of meat) with a lot of fat on it that are cheaper. So most of the time it's asking how much money you got to spend to survive. Depending on what you want to eat."* (Participant L.M.). Historically access to healthy foods was based on resource availability, community sharing, knowledge and skill, not on the access to currency. Although moving back to a traditional market system would remove the need for currency, the effects of colonization and resource depletion by the market economy has made this unrealistic. "... *we lost the actual traditional way of living and I don't know ... that we can't (get) back to that*

because there's no fish.... and then the pollution eh, like how good is the traditional stuff anymore you know ... they are talking about the mercury in all the fish and what people up north and we're getting sick with mercury from you know." (Participant G.X.).

The conceptualization of diabetes as a colonizing agent can be further extended to encompass the recommended approach to the treatment and management of diabetes. While the Aboriginal population is disproportionately affected by T2DM (Health Canada, 2010; Health Canada, 2001; Martens et al., 2002; Statistics Canada, 2002; Tjepkema, 2002), national guidelines do not recognize Aboriginal perspectives of health in the management of diabetes. These national guidelines maintain a western-based approach across mainstream and Aboriginal populations recommending the central approaches of diabetes management be; 1) self-management education, 2) self and medical monitoring of diabetes, 2) pharmaceutical therapy, 3) evidence-based physical activity, and 4) medical nutrition therapy for the management of diabetes. These approaches are Euro-centric, western medically-based approaches that do not little to integrate Aboriginal world perspective of health. Within the CDA's 2008 *Clinical Practice Guidelines for the Prevention and Management of Diabetes in Canada* there is only a cursory chapter, under the special populations section, discussing considerations for Aboriginal populations. Therefore although diabetes has become a burden on the Aboriginal population the favoured approach to the treatment and management of diabetes by the medical community remains predominantly western-based.

Organizing theme: Diabetes diet is unappealing

This organizing theme pertained to the diabetes diet being viewed as an unappealing way of eating by community members with diabetes (See Figure 5.3). It was felt that the way of eating for controlling diabetes was too restrictive and that foods and recipes recommended for diabetes management were not appealing. One participant described her dissatisfaction; " *Even those foods that are considered light and no fat and so far that food doesn't even taste good. I would rather eat the real thing and less*" (Participant M.L.). Another described a similar sentiment; "*Sometimes that diabetes cookbook you just want to take it and toss it out.* " (Participant E.E.).

Not only were foods found to be unappealing but recommended foods also included foods and food groups which were not originally in the traditional diet, such as milk and milk alternatives. This further added to the general lack of appeal with managing diabetes according to recommended guidelines.

Basic Theme: The pattern of healthy eating for diabetes is restrictive and unappealing.

Community members with T2DM viewed the recommended pattern of eating for diabetes as restrictive. The foods believed to be good for diabetes were viewed as unappealing to participants and their families. The challenges faced by community members with diabetes are reminiscent of what Barton, Anderson & Thommasen (2005) would describe as the extreme difficulty Nuxalk First Nation community members had making substantial dietary changes and adhering to a prescribed diet to manage T2DM.

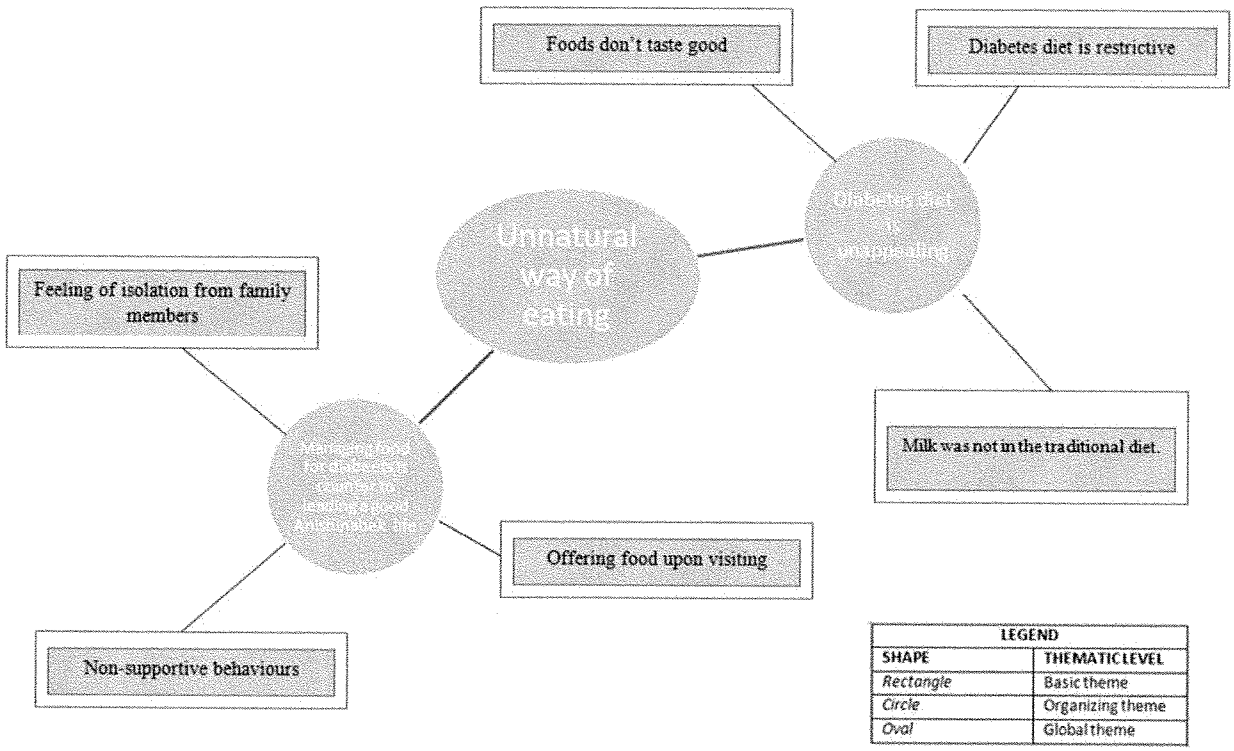

Figure 5.3: Thematic network for "Unnatural way of eating"

The preference for high fat foods was noted amongst several community members with diabetes and was described as a strongly ingrained taste preference in M'Chigeeng community members with diabetes. Boston et al. (1997) also found a strong preference for fatty foods, such as fatty meats and fish, amongst a sample of Cree Nation community members with diabetes.

A preference for high fat foods may increase the consumption of foods high in fat and calories. This may lead to a risk of weight gain, which is associated with increased insulin resistance and worsening glycemic control.

This preference was seen as running contrary to recommendations by local diabetes educators and diabetes guidelines. Indeed current dietary recommendations for the general population are to limit fat intake to <35% of energy equally apply to people with diabetes (Canadian Diabetes Association, 2008). Adults with diabetes are recommended to consume no more than 7% of total daily intake from saturated fats and limit intake of trans fatty acids to a minimum (Canadian Diabetes Association).

Savoca, Miller & Ludwig (2004) found that basic eating practices and meal planning activities that targeted reducing fat intake were associated with better glycemic control. See Table 4.1 for a description of the food habits pertaining to limiting fat intake that was related to lower HbA1C.

Nutrition Factors	Food Habits	Description
Basic Eating Practice	Reducing High Fat foods	Limiting snack foods, whole milk, pizza, chocolate, and fried foods.
	Choosing low-fat menu selections	Choosing broiled or baked main course,salads, vegetables, and low-fat dressing.
	Eating low-fat foods for breakfast	Choosing cold cereal, oatmeal, wholewheat bread, fruit, and hard cooked eggs.
Meal Planning	Eating low fat foods for lunch	Choosing vegetables, salads, fruit, tuna, chicken, low-fat lunch meats, and fat-free cheeses and dressings.

Table 5.2: Fat reduction strategies related to lower HbA1C (modified from Savoca, Miller & Ludwig, 2004)

A strategy often recommended by diabetes educators and national diabetes guidelines is to significantly increase the consumption of vegetables while decreasing the portions of other aspects of a typical meal. Several community members, however, admitted to eating few vegetables, citing a lack of satiety and preferences for other components of meals. This negative attitude towards non-starchy vegetables was noted by Boston et al. (1997) where Cree participants with diabetes stated that "*vegetables and salads did not seem to taste right*" and that "*the diabetic diet consists of mainly muskrat food*" (Boston et al., 1997).

A negative attitude towards non-starchy vegetables that leads to low consumption patterns may have a detrimental effect on glycemic control. Savoca, Miller & Ludwig (2004) found that food habits that increased vegetables were strongly correlated to a lower HbA1C (See Table 5.3).

Nutrition Factors	**Food Habits**	**Description**
Carbohydrate/Vegetable Strategies	Eating two vegetables for dinner	Choose two or more vegetables or a combination of one vegetable and salad at the main meal of the day.
	Eating large amounts of vegetables	Have vegetables at lunch and dinner, having more than two portions of vegetables at a meal, eating only vegetables as a meal.

Table 5.3: Vegetable related food habits related to lower HbA1C (modified from Savoca, Miller & Ludwig, 2004)

A lower intake of vegetables may lead to an increased intake of foods that are higher in calories putting individuals at risk of increasing weight. Garriguet (2008) reviewed the self-reported eating habits of the Aboriginal population compared to non-Aboriginal population using data from the 2004 Community Health Survey. The author found a statistically significant difference amongst Aboriginal women aged 19-50 years of age, noting one serving less per day of vegetable and fruit than the non-Aboriginal population (Garriguet, 2008). The lower intake of vegetables and fruit and other food groups was replaced by a higher percentage of calories from the "other foods" group. In fact, more than 35% of the average daily calories of Aboriginal women, aged 19-30 years of age, compared with 24% for non-Aboriginal women, came from the "others foods" group. Indeed the Aboriginal women replaced lower calorie foods with higher calorie choices in the "others group" as the difference in total calorie intake was 359 kilocalories.

Many community members with diabetes described a pattern of overeating prior to diagnosis of diabetes, large meal portions, and continued difficulty controlling food portions to manage blood glucose levels. Savoca, Miller & Ludwig (2004) found that diet strategies that limited meal portions were associated with lower HbA1C. Therefore a lack of portion control and dietary restraint may lead to poor blood glucose control in community members with diabetes. The practices the authors found associated with better glycemic control included; restricting the amount of food consumed at one time, limiting the size and frequency of dessert, limiting the amount of high sugar foods and avoidance of restaurants serving large portions.

Delahanty & Halford (1993) found that in the Diabetes Control and Complications Trial four nutrition behaviours were associated with clinically significant reduction in A1C (0.9%). Three

of these nutrition related behaviours were linked to dietary adherence to the prescribed meal and snack plan as well as not over treating hypoglycaemia.

Basic Theme: Milk shouldn't play a significant part in the Anishinabek diet, if at all.

Milk and dairy products were not viewed as a natural part of the Anishinabek traditional diet nor an important part of the contemporary diet for Anishinabek managing diabetes. This was supported by the fact that historically milk and dairy products were not consumed in the traditional diet and this lack of habituation caused the intolerance that the majority of Aboriginal people have towards the milk sugar lactose, found in most dairy products. One participant summed up the beliefs of several community members "*I will not drink milk that's just for the little ones and it's for the little calves ... Little cows ... They talk about that our bones, our bones ... need calcium but there are other ways to get that calcium.*" (Participant M.L.).

Most community members with diabetes reported a low intake of milk products, particularly fluid milk. This was confirmed by research by Garriguet (2008) who found that Aboriginal men consumed significantly less milk products than did non-Aboriginal men.

Organizing theme: Managing food for diabetes is counter to leading a good Anishinabek life

This organizing theme pertained to the idea that following dietary recommendations by health professionals and diabetes guidelines often ran counter to following Anishinabek cultural and familial norms (See Figure 5.3). This disagreement between Anishinbek norms and recommended guidelines may create internal conflict for individuals with diabetes and reduces the likelihood of following the recommended dietary guidelines to manage diabetes.

Choosing to follow the diabetes diet within the context of usual family meals and food related activities caused a sense of isolation in some community members. When family members engaged in non-supportive behaviours it further highlighted the division between the 'diabetic' in the family and the 'non-diabetics' within the family. Feelings of isolation may be detrimental to adherence to the diabetes dietary guidelines long term. Fisher et al. (2008) found that sustained adherence to diabetes management recommendations, including diet self-care, was related to family and wider social networks, not to clinical settings.

Larger family functions, often food-centric activities, are situations in which community members with diabetes may not feel fully engaged when following the diabetes diet. During feasts for example, cultural and familial norms often encourage consuming larger portions of food and eating until reaching fullness. These practices do not align with portion control guidelines set by diabetes educators for their Anishinabek clients. This may cause a sense of guilt

with community members during diabetes wellness visits when disclosing these food practices despite these practices being culturally appropriate and accepted. This guilt associated with cultural practices may hinder patient-provider relationship building when providers are seen as judging cultural practices and norms.

Global theme: Diabetes diet an unnatural way of eating

Two organizing themes emerged from the focus group data in this thematic network; 1) the diabetes diet is unappealing, 2) Managing food for diabetes is counter to leading a good Anishinabek life. These two themes elucidated the central theme; the diabetes diet is an unnatural way of eating for Anishinabek community members with diabetes (See Figure 5.3).

Nutrition therapy for diabetes, or the 'diabetes diet', is based on the Canada's Food Guide, which is a nutrition guide produced by Health Canada designed to help people of all ages choose their food wisely. The guide enables many individuals to meet their nutrient needs by following a simple daily food pattern based on 4 food groups (Health Canada, 2007). The Canadian Diabetes Association recommends a diet based on the food guide with a higher suggested intake of fiber, 25-50 grams, than the regular population (Canadian Diabetes Association, 2008).

The Anishinabek traditional diet, considered the natural way of eating for the Anishinabek, differs from the Canada's Food Guide; the First Nations, Inuit and Metis edition included. In

general, the traditional diet tended to be high in lean protein, low in fat and carbohydrate sources were derived from low glycemic index foods; consisting primarily of wild meats and fish; deer, moose, rabbit, and wild game birds, wild plants, corn, dandelions, mushrooms, and teas amongst others (Angela Shawanda, personal communication, March 2nd 2011). The Canada's Food Guide is often criticized by Aboriginal groups for its inclusion of milk and dairy products, a high recommendation of non-starchy vegetables, a high carbohydrate content (45-60% macronutrient distribution range), and low recommended servings of meat, fish and game birds (2-3 servings/day), all of which significantly differ from the traditional Anishinabek diet.

Therefore patterns of eating that deviate from the natural diet for the Anishinabek are often viewed as unnatural and not optimal to the health of Anishinabek community members. Although the Canada's Food Guide pattern to healthy eating and the diabetes diet are espoused by diabetes educators and dietitians as a healthy eating pattern for people with diabetes it is not viewed as natural by some community members and considered to be an imposed unnatural eating pattern. Furthermore, restricting eating behaviours (i.e. portion control) at family functions and cultural events is counter to cultural norms and usual family practices. This artificial imposition of dietary restrictions further adds to the unnaturalness of the diabetes diet. As long as the diabetes diet is viewed as unnatural and a threat to cultural and familial norms it will be viewed as undesirable.

Cultural events, ceremonies and foods

M'Chigeeng First Nation is undergoing a re-vitalization of cultural identity and increasing acceptance of cultural ceremonies amongst the community members (Geraldine McGregor-Ense, February 23 2010, personal communication). Cultural events and ceremonies have thus become ever important for reaffirming an Anishinabek cultural identity. Food has always been an important component of these cultural gatherings and to this day continues to be a key element of traditional ceremony and gatherings. The main cultural gatherings community members with diabetes described were the traditional pow wow and the traditional ceremonial fast.

The traditional pow-wow is a specific type of event where Aboriginal people meet to dance, sing, socialize, and honor Aboriginal culture. At modern day events, pow wows have many private food vendors present, providing a range of food items for sale. The spiritual fast is another cultural event. The fast is both spiritual and ceremonial in nature. The participant involved deprives oneself of food and beverages, for a specific amount of time, with water being allowed. Although the length of the fast is variable it may be up to 7 days. (Angela Shawanda, personal communication, July 13, 2011).

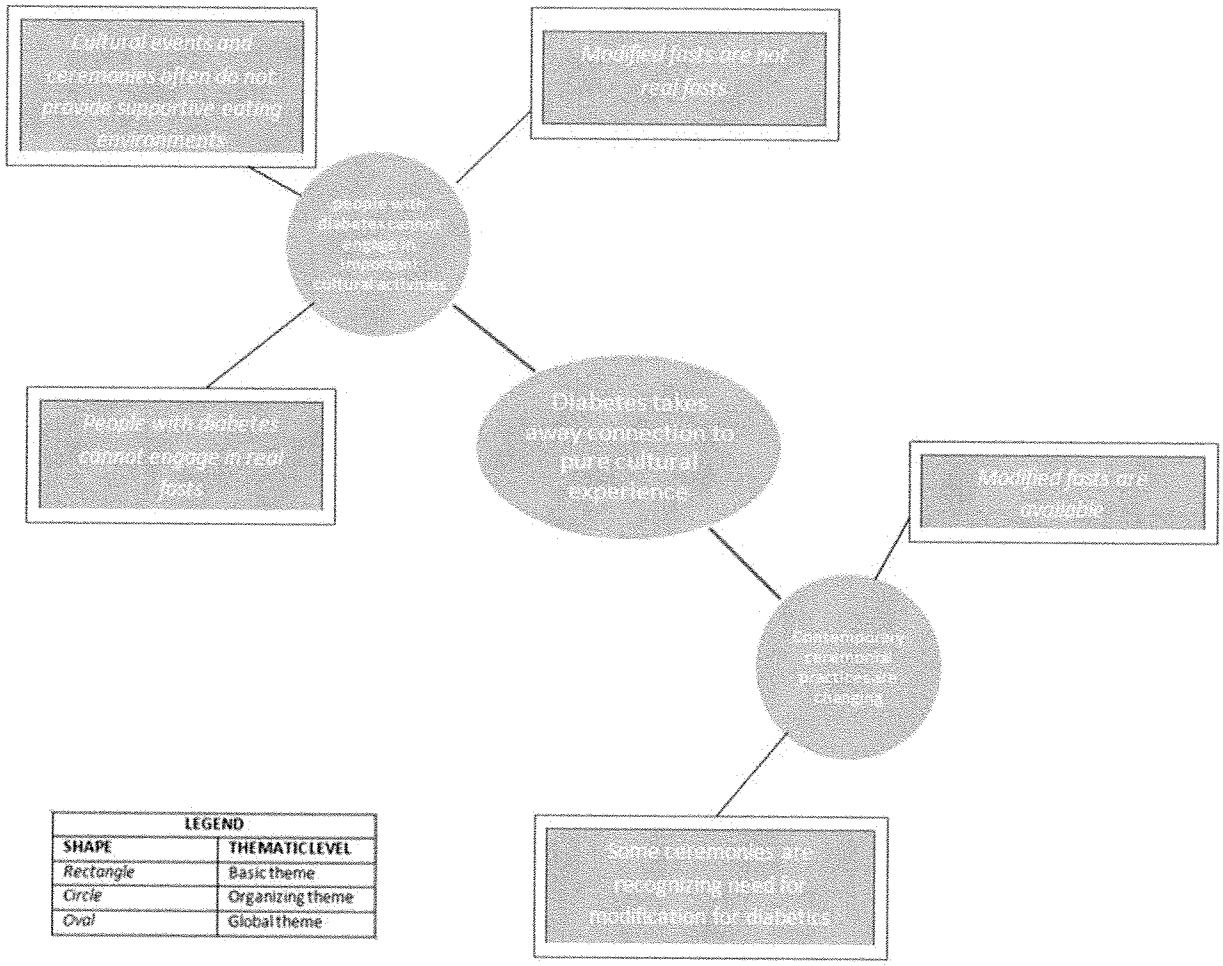

Figure 5.4: Thematic network for "Diabetes takes away connection to pure cultural experience"

Organizing theme: People with diabetes cannot engage in important cultural activities.

This organizing theme pertained to the theme that community members with diabetes felt unable to fully engage in traditional and contemporary cultural ceremonies and events (See Figure 5.4). The basic themes that emerged from focus group discussions included; 1) Pow wows are not

supportive eating environments, 2) People with diabetes can't do real traditional fasts, 3) Modified fasts are not real fasts.

The Canadian Diabetes Association Guidelines (2008) recommend a consistency of carbohydrate intake, appropriate meal spacing and regularity in meal consumption to assist with blood glucose control. Additionally, foods are recommended to be low in energy density to optimize satiety and discourage overconsumption (Canadian Diabetes Association, 2008). Both the pow wow and spiritual fast change individuals' usual dietary patterns which puts community members at risk of poor glycemic control. In general, those who over consume at pow wows are at risk of hyperglycemia, while those engaging in spiritual fasts while taking insulin and some sulfonylurea oral hypoglycemic agents are at risk of hypoglycaemia.

The recognition that these two cultural activities cause a significant change in dietary patterns and may affect blood glucose control likely contributes to the perception that community members with diabetes cannot engage in these activities if they are to maintain optimal blood glucose control. Furthermore, ongoing reinforcement by diabetes educators about adherence to the diabetes dietary guidelines may reinforce the idea of non-participation.

Basic Theme: Cultural events and ceremonies often do not provide a healthy food environment for community members with T2DM.

According to community members the traditional pow wow does not provide a supportive environment for people trying to manage their diabetes. Participants described a lack of healthy

options to choose from at the traditional pow wow ."*...the pow wows have gotten 'fast food-icized'; (be)cause if anything is bad for you it's that god damn 'Indian taco'*" (Participant Y.U.).

The lack of healthy food choices at pow wows and reliance on high fat foods may result in worse blood glucose control in community members with diabetes. Savoca, Miller & Ludwig (2004) found that the challenges of eating out were strongly correlated to a lower HbA1C. Factors related to worse blood glucose control while dining out can be seen in table 5.4 below.

Nutrition Factors	**Food Habits**	**Description**
Challenges of Dining Out	Eating at buffet, fast-food, and large chain restaurants	Eating at restaurants featuring large portion sizes of food, high-fat foods, and limited selection of vegetables.
	Choosing high-fat or high-carbohydrate menu selections	Choosing fried foods, high-fat meats, sauces, pasta, bread, and gravy.
	Eating high-fat sources of protein	Selecting red meat, fried meat, seafood, fish, and processed meat.

Table 5.4: 'Challenges of dining out' food habits related to lower HbA1C (modified from Savoca, Miller & Ludwig, 2004)

Community members with diabetes described various strategies for diet self-care while at the pow wow. Several participants, however, stated that they didn't adhere to their diabetes diet. Many participants described non-adherence to their diabetes diet by overeating or lack of portion control. For some this caused poor glycemic control; *"I would say at Pow Wow (my blood sugars are higher). Cause they have all these foods and you want to try everything. I know I do*

it. "(Participant K.T.).

Attempts at managing diabetes by avoidance or limiting exposure to cultural community events may cause feelings of isolation and non-inclusion for people with diabetes. Boston et al. (1997) found that Cree community members with diabetes did not feel like they could fully participate in cultural feasts while adhering to their diabetes diet *"... feasts... (are an) integral part of Cree life and Cree heritage, cannot be fully enjoyed or receive full participation from Cree with diabetes because of the constraints of diet"* (Boston et al., 1997) Cree community members with diabetes stated that full participation in feasts was important and described a sense of "*feeling different*" when having to limit their dietary intake due to diabetes (Boston et al.).

Organizing theme: Cultural adaptation for people with diabetes is occurring

This organizing theme pertained to the theme that cultural adaptation for people with diabetes is occurring (See Figure 5.4). The basic themes that emerged from focus group discussions included; 1) modified spiritual fasts are available for community members with diabetes, 2) some ceremonies are recognizing the need for change to accommodate individuals with chronic disease.

The fact that there is active adaptation and accommodation of community members with diabetes suggests recognition by the traditional Anishinabek community that diabetes is a major issue. Furthermore, it suggests that there is recognition that chronic disease, such as diabetes, limits community members' participation in traditional cultural ceremonies, which requires

contemporary cultural adaption to be more inclusive. Several participants were not aware of modified ceremonies for community members with chronic illness. Once made aware, all participants agreed that this was a positive development to promote cultural inclusion of community.

Global Theme: Diabetes takes away the pure cultural experience

Two organizing themes emerged from the focus group data in this thematic network; 1) Diabetics cannot fully engage in ceremonies and events, 2) Contemporary ceremonial practices are changing for diabetics (See Figure 5.4). These two organizing themes exposed the central theme of diabetes taking away pure cultural experience.

Full engagement in ceremonial and cultural events allows individuals to express and celebrate their Anishinabek cultural identity. However, a number of community members with diabetes felt that it was necessary to avoid or modify cultural experiences to accommodate their diabetes dietary guidelines. Despite partial involvement in unmodified cultural events or full involvement in modified cultural events various community members with diabetes did not feel this was a pure cultural experience; "*I've been fasting even in my diabetes but I've been just given liquids (fruit and/or vegetable juices) but I don't think that's the real fasting.*"(Participant M.L)

This perceived barrier to engaging in Anishinabek cultural events and ceremonies may threaten an individual's cultural identity and be a source of conflict with the chronic condition. Diabetes educators unaware of this possible conflict may risk damaging the patient-provider relationship if

diabetes guidelines are positioned as superseding cultural experience. Instead diabetes educators should be vigilant to a possible conflict between diabetes and cultural identity and expression through participation in cultural activities and support community members with diabetes in fully engaging in these activities in a safe way while maintain euglycemia.

Family and diabetes dietary management

In Anishinabek culture the family is an important part of wellness. The family unit includes both immediate family as well as extended relatives. In other cultures family and friends have been found to make an important difference in diabetes management (Choi 2009; Fisher, Chesla, Bartz, Gilliss, Skaff & Faa, 1998; Jones et al, 2008; Wen, Shepherd & Parchman, 2004). In fact, research has found that sustained adherence to diabetes management recommendations are related to family and wider social networks, not to clinical settings (Fisher, Chesla, Bartz, Gilliss, Skaff & Faa, 1998).

It was apparent from discussions with community members with diabetes that family has a great influence over food and meal choices available, ultimately affecting diabetes control. Family both provided behaviors that supported diabetes diet self-care and behaviors that were non-supporting.

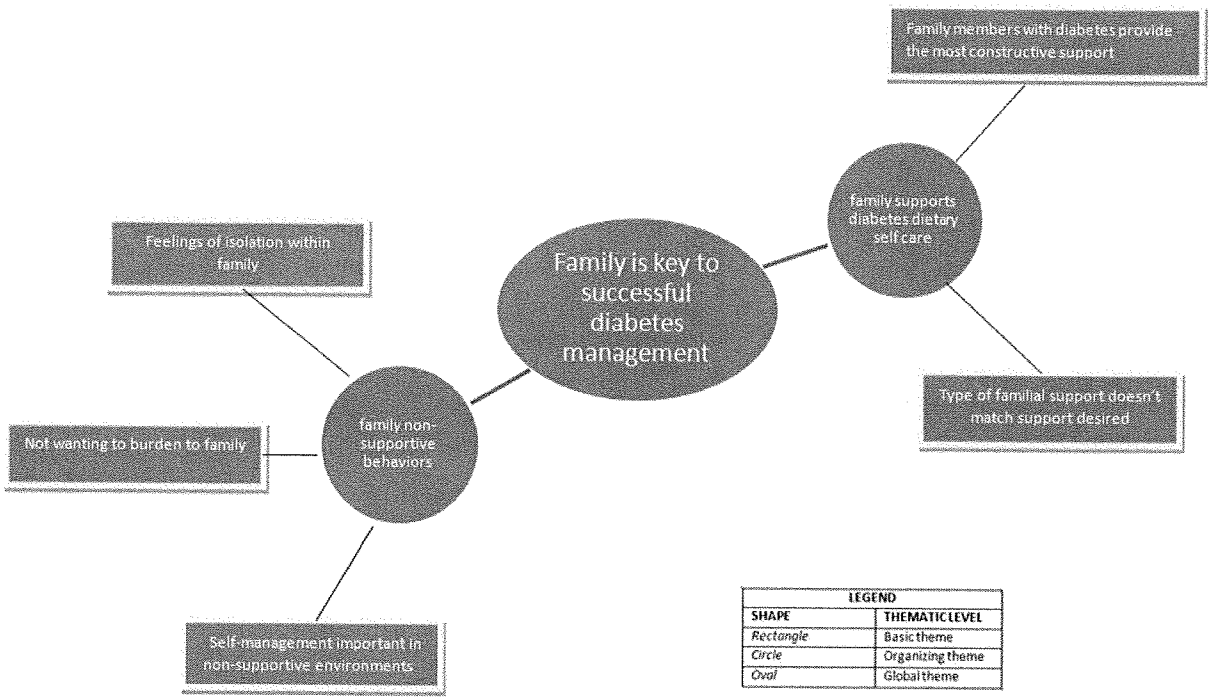

Figure 5.5: Thematic network for "Family is key to successful diabetes management"

Organizing Theme: Family supports behaviors of diabetes diet self-care

This organizing theme pertained to the theme that family was a source of support for their family members with diabetes (See Figure 5.5). Similar findings were described in the literature where the authors found that higher levels of perceived family support was associated with higher reported levels of diet self-care (Gilliss, Skaff & Faa, 1998; Wen, Shepherd & Parchman, 2004). Choi (2009) found that a higher level of family support with the diet was significantly associated with lower HbA1c, confirming the beneficial effect of family support with the diet and glucose control.

The basic themes that emerged from focus group discussions included; 1) Type of familial support doesn't match support desired, 2) Family members with diabetes provide the most constructive support.

Basic Theme: Type of familial support doesn't match support desired.

The most common type of supportive, as well as non-supportive behaviors, described by community members with diabetes was that of information provision or monitoring. In some instances, family members did not go beyond this level of assistance despite a need for more support. One participant described her situation in which her husband provided strict diet monitoring but did not provide family support by changing household food practices; *"(My husband) watches me like a hawk. He makes sure I use the right stuff and then I told him what's the sense of buying ...(unhealthy foods for you) if I can't eat it. Well I ain't going to buy it (then) nobody can have it." ... "* (Participant D.D.).

Despite cultural differences these finding were similar to that observed by Carter-Edwards, Skelly, Cagle & Appel (2004). The authors found that people with diabetes had a perception that family members lacked an understanding of their needs and how to most appropriately support them. Participants in that study believed that those who provide support claim they care and try to be helpful but provide minimal physical assistance or emotional understanding of their needs. The authors concluded that "*Those who provide informational support seem to care but misunderstand the type of information actually needed and how to best deliver it.*"

Basic Theme: Family members with diabetes provide the most constructive support

Community members with diabetes encountered supportive and non-supportive behaviors from a wide array of relations; friends, spouses with diabetes, spouses without diabetes, family with diabetes, and family without diabetes. Of the mentioned relations participants described family members with diabetes as providing the most constructive support. Support came in the form of role modeling, providing diabetes diet-friendly environment and positive encouragement. One participant described his positive support from immediate family with diabetes; *"My mother has diabetes and my brother has diabetes so when I go visit them we're eating pretty healthy. They eat good around me."* (Participant D.E.).

Another participant described her large supportive network of family members with diabetes which allowed for improved dietary adherence despite a lack of preference for meals deemed diabetic-friendly; *"Oh, I think it's pretty good when I go to family because the majority of them are diabetic and they really take it serious. Sometimes you go and it's really bland and yucky. But you know that it is diabetic cook book (recipe) or whatever. So for me going to my family is pretty good because they are pretty good in taking care not cooking some stuff."* (Participant E.E.).

Organizing theme: Family engages in non-supporting behaviors

This organizing theme pertained to the theme that family engaged in non-supportive behaviors that hindered their family members with diabetes in following diabetes diet guidelines (See Figure 5.5). The basic themes that emerged from focus group discussions were; 1) feelings of isolation within the family, 2) self-management is important in a non-supportive environment, 3) not wanting to burden family with diabetes diet.

A sense of conflict around acceptable foods and meals was described by community members with diabetes and their families. This conflict created a struggle between family members as they tried to control the foods and meals available, creating stress between community members with diabetes and their spouses and other family members. Jones et al. (2008) similarly described family as being a barrier to adhering to dietary guidelines amongst a sample of African American women with T2DM.

Another non-supporting behaviour that family members engaged in was that of excessive monitoring of food and dietary habits of their relatives with diabetes. It was generally believed that family members meant well, however participants found it intrusive, controlling and unwelcome. This type of non-supportive behaviour is termed controlled motivation within the Self-Determination Theory (SDT) paradigm (Julian & Senecal, 2009). Controlled behaviors are described as behaviors that are "initiated and regulated by environmental pressures such as reward structures, which may be internalized as imperatives of how one 'should' or 'must behave' " (Julian & Senecal). For, example, people who are controlled may follow the

recommended diet only because their spouse would be mad if they made poor dietary choices. SDT proposes three broad categories of motivation: autonomous motivation, controlled motivation and a-motivation. Individuals that function autonomously perform behaviors that are self-initiated; their behavior is important to them and ties into their values and goals systems (*ibid.*). People with diabetes who are a-motivated to follow their dietary plan are those who are not motivated at all. Julian and Senecal (2009) found that people with diabetes that were autonomously motivated, relative to controlled motivation or a-motivation, predicted better health outcomes. Thus controlled motivation, in the form of unsolicited information about managing their diabetes and close monitoring by family members, may be a less effective way of family members trying to support their relatives with T2DM.

Kokanovic & Manderson (2006) found that women with diabetes sometimes resisted attempts by family members to supervise their diabetes diet self-care as they sought to maintain control over their lives. Women often avoided talking to immediate family to avoid being monitored, scolded or treated as a 'patient'. A mother and daughter pair described their struggle for control; "*When she (mother) goes to the grocery store she heads straight for the cake. And I'm taking them out. By the time she gets to the counter they are all back in. I'm like you can't have that. Now that I've got my own place she's got a whole stack of (unhealthy) stuff. I seen her.*" (Participant K.T), (mother) "*I can eat what I want now.*" (Participant D.D.).

Basic Theme: Feelings of being isolated because of diabetes within the family.

Community members with diabetes described feelings of isolation and exclusion in their family due to having to follow diabetes dietary guidelines for self management while non-supportive family members continued to engage in usual eating patterns and behaviors. This sentiment was found by Boston et al. who found in a Cree community many respondents talked about feelings of isolation from not being able to join in traditional Cree social activities organized around eating which were described as "*a vital part of the maintenance of family cohesion and unity.*" Therefore community members with diabetes may find it particularly challenging to follow diabetes diet self-management practices in a family that lacks understanding or is not willing to accommodate the new responsibilities of dietary self-management practices that a newly diagnosed family member needs to engage in.

Family relations are important in the Anishinabek culture as in many Aboriginal cultures. Maintaining these strong familial ties through regular visitations with relatives is thus an important part of the culture. Large family gatherings are typically organized around eating or 'feasts'. Even shorter informal visitations have food as a central theme. The offering of food to relatives or guests is an important cultural practice. The acceptance of the food is a culturally expected social norm. To not accept the food is seen as insulting (Angela Shawanda, Diabetes Nurse Educator, personal communication, Oct 6 2010). To this end community members with diabetes have cultural pressures to accept foods even when it does not fit in with their diabetes diet. Similar social norms were described by Boston et al. (1997) where respondents informed researchers that while diabetic teaching requires strict maintenance of a "diabetic diet", for Cree

people *"to be polite and respectful"* still means to join in social eating. To openly *"refuse food is to be disrespectful."* Therefore local diabetes educators who are recommending that community members with diabetes refuse offerings of food during family visitations are asking community members to break social norms putting the community members in an uncomfortable position.

Basic Theme: Self-management is vital when visiting family

The majority of community members with diabetes felt that they were primarily responsible for their diabetes self-care in family situations. One participant described his reliance on self to maintain his diet; *"Yeah... (my wife)... makes bread but she doesn't have the problem with diabetes, she doesn't have no diabetes. She's been tested, retested and over tested for diabetes, can't find an ounce in her. So...I have to look after myself at the table ... be mindful."*(Participant V.M).

This position is supported by evidence that demonstrates the effectiveness of self-management for improving glycemic control (Norris, Engelau & Narayan, 2001; Norris, Lau, Smith, Schmid & Engelgau, 2002). In fact, the Canadian Diabetes Association (2008) recognizes that self-management is the cornerstone of diabetes care and states that, *"self-management education that incorporates knowledge and skills development (including problem solving) ... should be implemented for all individuals with diabetes."*

An opposing view was proposed by one participant who felt that the primary responsibility was upon the individual primarily responsible for food procurement and preparation and in his case

was his wife. In this participant's case however this resulted in poor adherence to recommended dietary guidelines; *"...at home, you're not going to quit eating because your wife made something different. She knows your diabetic. What you're supposed to eat and what you're not supposed to eat. They know ... (the dietitian) gave me a paper like what you're supposed to eat, kind of have and have not and supposed to have. She usually doesn't follow that."* (Participant R.W.).

Basic Theme: The desire to not be a burden to family members they were visiting with the dietary needs

In a non-supportive environment participants continued to espouse self-management as key to diabetes dietary management. Interestingly, several participants mentioned a wish not to burden family with their dietary restrictions in a family environment that did not follow diabetes dietary recommendations. One participant illustrated this perspective; *"Well. I don't know. I'm not going to be there very long. I'll just say when I go home I'll cook my own stuff the right way. I'm not going to bother yous (sic) to make it right for me. I'll just let it go you know I'll just watch my ... what I'm going to eat that'll help me to get by but when I get home I'll cook my own. But I wouldn't put them down for it I'd say that's ok Ill just pick what's supposed to be good for me out of what you cooked. I'm not going to bother yous (sic) because I'm a diabetic ... I just tell them Ill just get along with it."* (Participant R.K.).

This unanimous strong desire not to burden other family members with their diabetes dietary restrictions highlights the strong emphasis on family over individual in the Anishinabek culture.

The Canadian Diabetes association emphasizes the need for individualized nutrition therapy and meal planning that accommodates the person's preferences, age, needs, culture, lifestyle, economic status, activity level and readiness to change (Canadian Diabetes Association, 2008). In general, the association recommends a healthy diet based on the *Eating Well with Canada's Food Guide* (Canadian Diabetes Association). Although sufficiently broad to accommodate a variety of familial situations, these recommendations position the individual with diabetes as the central consideration for dietary change which has ramifications to cohabitating family members. This may be a counter-intuitive position for individuals with diabetes as Anishinabek cultural values place greater importance on the family unit as a whole rather than the individual particularly in situations where the entire family is affected by decisions by individual family members. Individual dietary changes may affect a number of dietary factors including; the foods available to other family members, the burden on family members responsible for food preparation and food procurement, and budgetary pressures. Although positive dietary change recommendations by health professionals are well meaning they may unknowingly cause a friction between family members when lifestyle changes are made that places the individual ahead of family cohesion.

Global Theme: Anishinabek family is key to successful diabetes management.

The cultural importance of family and close familial connections was highlighted by key informants and focus group participants. The importance of family is amplified in the diabetes self care model as familial influences were found to either enhance or hinder dietary adherence. In a supportive environment people with diabetes are more likely to have improved adherence to

diabetes dietary recommendations, less likely to feel like a burden to family and less risk of feeling isolated within the family unit. In familial environments where there were low levels of support community members with diabetes have lower levels of dietary adherence, feelings of isolation and being a burden to family. Thus supportive environments may promote familial cohesion and support cultural well-being while non-supportive environments may have an opposite effect on culture wellbeing.

The integral role of family plays in self-care was noted in other populations as well (Choi 2009; Fisher, Chesla, Bartz, Gilliss, Skaff & Faa, 1998; Jones et al, 2008; Wen, Shepherd & Parchman, 2004). The importance of family in the Aboriginal world may play a dual role; that is in supporting diabetes self-care as well as supporting cultural well being due to the high value placed on family.

Chapter Six: Conclusions

6.1 Conclusion

The purpose of the study was to discover culturally shared local beliefs and attitudes towards foods that may impact acceptance of dietary recommendations for the management of Type 2 Diabetes (T2DM) amongst Anishinabek in M'Chigeeng First Nation. Research questions included exploring the perceived relationship between traditional foods and T2DM, the influence of cultural gatherings and ceremonies on food consumption/choices and nutrition management of T2DM, as well as to explore family dynamics and its influence on the dietary management of T2DM.

Overall, culturally shared beliefs and attitudes about diabetes and foods may impact acceptance of dietary recommendations for the management of T2DM amongst community members with diabetes in M'Chigeeng First Nation.

Diabetes was conceptualized as a colonizing agent; a foreign disease which often caused feelings of fear and a loss of sense of control over one's life. A lack of perceived control of diabetes caused fear and often led to less optimal dietary management. In dealing with a diagnosis of diabetes community members with diabetes may feel an attack to cultural identity when being inflicted with a 'foreign disease'.

Strong beliefs exist within the community that the transition from a predominantly traditional diet to a processed, western food-based diet was a major contributing factor in the development of diabetes in M'Chigeeng First Nation. The connection between good health and traditional foods went beyond nutrition as it was also believed that the act of gathering and preparing the traditional food was also beneficial to blood glucose control. Additionally maintaining a connection with the land was important to community members.

Despite the high health value and historical significance of traditional foods it was generally believed that community members would not go back to a traditional way of eating. This was due to many factors including a habituation to contemporary conveniences, preferences for modern foods, limited natural hunting and fishing resources, and the contamination of the environment.

Cultural gatherings are an important part of Anishinabek culture. Recently there has been a revitalization within the community to promote more use of traditional foods and re-establishing cultural ceremonies. The two main cultural gatherings of significance to many community members in M`Chigeeng included the traditional pow wow and the traditional fast. A major theme of diabetes taking away from pure cultural experience as community members described the difficulty they had managing their diabetes while attending pow wows and partaking in other cultural events and ceremonies. Traditional fasts were seen as inappropriate for people with diabetes in the traditional form however contemporary versions have seen modifications by some traditional healers to accommodate chronic diseases. This was viewed as a positive cultural development.

The idea of the Diabetes diet being an unnatural way of eating for Anishinabek community members emerged as a global theme. The 'diabetes diet' was believed by many community members as restrictive and unappealing. Difficulties encountered included having to limit portions at meals and the avoidance of fatty foods which were described as desirable amongst many community members.

Although academic literature supports the importance of spousal and familial support in the diabetes diet self-care; in practice this is commonly overlooked by diabetes educators. In fact, Anishinabek family was highlighted as a key to successful diabetes management. Currently diabetes education counseling sessions and workshops for Aboriginal community members are designed for individuals rather than designed to promote the inclusion of family members. This is a great systematic error in light of the great importance of family and community in the Aboriginal world-view. Diabetes educators, particularly those of non-Aboriginal ancestry, need to be cognizant of social norms surrounding food and family in order to guide community members with diabetes to better glycemic control without concurrently pressuring community members to break social norms related to eating and family.

6.2 Recommendations

Based on the conclusions of the research and input from the local research steering committee the following recommendations are made to the appropriate stakeholders.

Recommendations for Diabetes Educators / Dietitians

For clients with diabetes:

1) Recommend the provision of cultural safety training to diabetes educators and dietitians working with community members with diabetes. Promoting increased cultural competence amongst diabetes educators may lead to improved patient-provider relationships which may promote more honest self-disclosure, improved trust, better health care visit attendance and adherence to treatment plans and lifestyle goals.
2) Recommend promoting the use of traditional foods, based on access, availability and individual skill level. Increasing the use of traditional foods could improve the nutritional quality of the overall diet of community members with diabetes, promote physical activity associated with the procurement (hunting, gathering, fishing, etc.) of traditional foods and enhance spiritual wellbeing by strengthening cultural identity.
3) Recommend providing community members with access to appropriate resources from local or national fishing/gaming management agencies regarding the safety of consuming local foods. This would provide accurate and relevant information regarding the safety of

fishing and wild game resources as it pertains to environmental pollution and contamination.

4) Create awareness of the availability of modified traditional fasts for people with diabetes. Having the opportunity to partake in cultural ceremonies may promote cultural identity, a sense of community inclusion that can enhance spiritual well being.
5) Recommend providing skills based cooking workshops that can provide community members with diabetes with experience creating healthy and flavorful meals. This may lessen negative attitudes that individuals have towards following the dietary recommendations for diabetes.

For family of clients with diabetes:

1) Recommend the development of a family based counseling model in diabetes education / dietetic nutrition counseling that is culturally acceptable. This counseling model would recognize the strong influence of family members and importance of familial support in the success of diabetes dietary management. Continuing to concentrate primary health care efforts exclusively on individual patient-provider interactions would not recognize the reality of home life for many Aboriginal community members with diabetes.
2) Recommend the development and promotion of skills-based diabetes nutrition education workshops to increase the sense of control community members and their families have over diabetes. By providing community members and their families with

positive learning experiences in the realm of dietary management of diabetes in a safe environment, diabetes educators can promote increased self-efficacy.

3) Recommend providing family members with strategies and skills to properly identify the form of support that would best assist their family member with diabetes.
4) Recommend providing family members with skills to provide varying types of support for the individual with diabetes; i.e. emotional, physical, informational support, etc. Encourage family members to limit use of controlled motivation as it is less effective and can lead to the individual with diabetes avoiding family members and feeling resentment.Since non-supporting behaviors were reported regularly by community members with diabetes equipping family members with strategies and skills to assist with diabetes management would be a big asset.

For community:

1) Recommend that diabetes educators and/or dietitians provide diabetes health information booth at traditional Pow Wow. Emerging from recommendations provided by focus group participants, thisform of support has the potential to connect community members with local diabetes resources at a time when community members with diabetes are faced with a poor food environment. By feeling able to more fully participate in cultural community events it may enhance a sense of spiritual well being and cultural identity.

Recommendations for Policy makers/ Community advocates

1) Advocate for initiatives that support the promotion of traditional foods and for harvesting and preparation skills acquisition. A lack of skills in harvesting and preparation of traditional foodswere cited as barriers to their use.Providing opportunities for this knowledge acquisition for traditional foods skill set may promote increased consumption of traditional foods which can improve the diet quality of community members with diabetes.
2) Contact Pow Wow planning committee and recommend the providing incentives for vendors providing healthier food choices.

6.3 Limitations

This research has some limitations. The representativeness of the sample is of some concern. The participants were contacted from a confidential community list of individuals diagnosed with T2DM. In addition a variety of methods of recruitment was used; including newsletter advertising, posters, personal face-face invitations, however most participants indicated that they had responded to the personal telephone invitations. Thus there is a selection bias towards individuals with the finances to afford telephone services. Although participants included the unemployed, disabled, retired and employed, a bias against individuals with extreme poverty is likely. Additionally the number of participants gainfully employed was underrepresented with the participant sample predominately composed of unemployed, disabled and retired community

members. The possibility of missing the perspective of employed individuals who possibly possess high levels of education is a potential weakness in the sample.

Furthermore, as discussed earlier, my well-known role in the community as a Registered Dietitian may have impacted the focus group data due to my professional role affecting participant disclosure despite a concerted effort to minimize its effect.

6.4 Delimitations

Contemporary Aboriginal shared food beliefs and attitudes are influenced by historical and contemporary food systems. Since contemporary food systems and degree of change from a historical state vary by region and community, as well as from region, community to community, by rural versus urban, and on-reserve versus off-reserve status, dietetic practitioners need to be careful generalizing results to other Aboriginal populations. Since the term Aboriginal people recognizes three constitutionally separate groups; Status Indians, Métis people and Inuit, each with a unique set of heritages, languages, cultural practices and spiritual beliefs, it would be ill advised to apply conclusions from research with one group to another. Therefore conclusions may be more applicable to Aboriginal groups legally termed Status Indians, or the preferred term '*First Nations*'.

Generalizability of the study results is most appropriate for the adult Anishinabek (Ojibwe) population with T2DM that share similar environments to the study population. The differences in cultural beliefs between First Nation communities are noted in the literature. While Boston et

al (1997) found a preference for fatty foods based predominately on beliefs of health benefits from fatty wild meats amongst Cree community members with T2DM, the current research with Anishinabek study participants showed a taste preference for fatty foods not sourced from traditional sources but rather from cultural and/or contemporary foods. No health benefits were believed to be gained from eating these fatty foods by the participants. Using culturally safe diabetes nutrition education practices these two cultural beliefs would require different approaches. Similar undocumented cultural differences may further limit the generalizability to other First Nation groups.

Aboriginal communities across the nation have various challenges with access to foods, with varying distances to food sources and varying costs associated with procuring food. Although affordability of nutritious foods was mentioned by some research participants this topic was beyond the scope of the current research project. Additionally participants discussed in depth the role of physical activity in managing T2DM, however, similarly this topic is not explored in the current research due to the focus on cultural beliefs and attitudes of food and nutrition.

6.5 Future Directions

This thesis has served to provide a deeper understanding into cultural beliefs and attitudes of diabetics towards foods that affects the acceptance of dietary recommendations for the management of T2DM. Essentially, contemporary diabetes nutrition education overlooks the importance of family, cultural norms related to food, and specific food beliefs that affect the acceptance of adhering to a diabetes diet. Additionally, the struggle community members with

diabetes have at family and cultural gatherings are under appreciated and affects community members' dietary self-care and well being.

Future research in this area would benefit from including participants underrepresented in the sample. These would include community members with diabetes who are employed and with higher levels of educational attainment. This may provide further rich qualitative data not gathered from the sample.

An exploration of the role of family is particularly important in the Aboriginal population because of the importance of family and community, as opposed to the individual in this culture. Therefore more inquiry into the experiences of Aboriginal family members of individuals with diabetes is warranted. Gaining a better understanding of the experiences of family members would allow diabetes program planners to develop more family-centered workshops that address the educational needs if those caring for and supporting family members with diabetes.

Another area of interest is how attitudes and beliefs change over the passage of time with diabetes, from diagnosis to years after post-diagnosis. In practice practitioners have noted people with diabetes going through cycles of moderate to intense self-care to periods of relatively little to no self-care. Exploring the motivators and de-motivators that trigger moving from one intensity of self-care to another may inform diabetes educators how to best guide Aboriginal community members with diabetes to optimal well being.

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APPENDICES

APPENDIX A

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CONSENT FORM – Focus Group

I have read the information presented in the information letter about a study being conducted by Zsolt Toth, Lakehead University in collaboration with Noojmowin Teg Health Center and M'Chigeeng Health Services.

I understand that I am participating in a focus group to discuss the food beliefs, attitudes and Type 2 Diabetes Mellitus.

I have had the opportunity to ask questions about my involvement in this study, and to receive any additional details I wanted to know about the study. I understand the risks and benefits of participating in this study. I understand that I may withdraw from the study at any time, if I choose to do so. I have been given a copy of this form.

I consent to the taping of this session.

I understand that the results of the research may be published and that participants identities will remain anonymous.

I understand that a copy of the report will be made available to me, which will be available at M'Chigeeng Health Services after August 2010.

I understand that the confidential information will be stored at Lakehead University for a period of five years.

Date:_____

_____ _____

Signature of Participant Name of Participant

APPENDIX B

Letter of Information – Focus Group

Food beliefs, attitudes and commonly consumed foods of Ojibwe community members with Type 2 Diabetes

Graduate Student Investigator **Zsolt Toth, RD, MPH (candidate)**
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Community Organization Noojmowin Teg Health Center (Pamela Williamson)
M'Chigeeng Health Services (Roger Beaudin)

Funded by: 1) Canadian Foundation for Dietetic Research
2) Toronto/McMaster University Indigenous Health Research Development Program, funded by the Canadian Institutes of Health Research-Institute of Aboriginal People's Health

Dear Potential Participant,

My name is Zsolt Toth and I am a Masters of Public Health student at Lakehead University. I will be conducting a research study on the food beliefs, attitudes and practices of M'Chigeeng First Nation community members with Type 2 Diabetes that may affect diabetes control. This will provide insight into the relationship between food and health from an Aboriginal world perspective. This research has the potential to provide information that can improve Diabetes Educator-patient interactions. Also understanding food beliefs and attitudes can be used to promote healthier dietary intakes amongst Aboriginal community members with Type 2 Diabetes.

Procedures involved in the Research

I would like to conduct a focus group with you. A focus group is a group discussion about one topic. I will ask you and others about your beliefs and attitudes towards foods and how they may affect the control of Type 2 Diabetes. The focus group will take 90 minutes and have between 5 - 6 other research participants. In order to ensure the accuracy of my note taking I would like to audio record this interview.

Potential Harms, Risks or Discomforts:

It is not likely that there will be any harms or discomforts associated with participation. There may be a chance that other community members who know you well may be able to attribute your quotes to you. For this reason we ask that you only share information that you would feel comfortable sharing within a group. You do not need to answer questions that make you uncomfortable or that you do not want to answer.

Potential Benefits

Individual Benefits:

As a participant you will be given the chance to influence future diabetes nutrition programming and cultural training for Diabetes Educators based on your own cultural food beliefs and management of Type 2 Diabetes through diet.

Regional Benefits:

This research has the potential to provide information that will allow for the development of more culturally appropriate community nutrition programming for Anishinabek community members on Manitoulin Island with Type 2 Diabetes. In addition, it has the potential to improve the cultural sensitivity of Diabetes Educators and other health care professionals working with Anishinabek community members with Type 2 Diabetes.

Payment or Reimbursement:

There is a $20 honorarium provided for your participation.

Confidentiality:

Anything that you say or do in the study will not be attributed to you personally. Anything that we find out about you that could identify you will not be published or told to anyone else, unless we get your permission. Your privacy will be respected and protected. We will ask the other research participants of the focus groups keep what you say confidential, but cannot guarantee they will do so. The information obtained will be kept in a locked filing cabinet at Lakehead University for 5 years. The raw data will be only available to the investigators team for research purposes only.

Participation:

Your participation in this study is voluntary. It is your choice to be part of the study or not. If you decide to participate, you can decide to stop at any time, even after signing the consent form or part-way through the study. If you decide to stop participating, there will be no consequences to you and information you provided will be removed from the stidu. If you do not want to answer some of the questions you do not have to, but you can still participate in this project in the future. Your decision whether or not to participate will not affect your access to services.

Dissemination:

The results, without identifying information, will be released in the form of results in the Noojmowin Teg Newsletter and M'Chigeeng Health Services Newsletter. Additionally a full report will be available at M'Chigeeng Health Center, and at a press release event in M'Chigeeng First Nation.

Publishing of Research

I wish to publish and make public presentations based on the results of the research. Your identity and that of other participants will remain confidential.

Information about the Study Results or Participating:

You may obtain information about the results of the study by contacting Zsolt Toth at 705-368-2182 ext 233, Pamela Williamson at 705-368-2182 ext 204, or Roger Beaudin at 705-377-5347. You can request a copy of the research report after October 2010.

Information about Participating as a Study Subject:
If you have concerns or questions about your rights as a participant or about the way the study is conducted, you may contact:

Lakehead University Research Ethics Board, Lakehead University, Thunderbay, ON, 955 Oliver Road, P7B 5E1.Telephone: 1-807- 343-8283

Lenore Mayers, Program Coordinator, Research Ethics Committee
Noojmowin Teg Health Centre, Aundek Omni Kaning, ON, Postal Bag 2002, POP 1K0
Telephone: 1-705-368-2182

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FOCUS GROUP GUIDE

Project Title: Food beliefs, attitudes and commonly consumed foods of Ojibwe community members with Type 2 Diabetes in North Eastern Ontario.
Project Date: 2009-07-09
Method: Focus Group
Topic: Food beliefs, Ojibwe, Type 2 Diabetes Mellitus
Principal Investigator(s): Zsolt Toth, RD, MPH (candidate) (zsolt.toth@noojmowin-teg.ca)

Instrument Title: Focus Group Discussion Guide
Total Participant time required: 1 hour + 10 minutes – 1 hour + 30 minutes
Break: 0 minutes

Overall question to answer in Focus group discussions:

The purpose of the study is to conduct qualitative research:

- To discover culturally shared local beliefs and attitudes towards foods that may impact glycemic control of Anishinabek community members with Type 2 Diabetes.

Below is a general *guide for leading our focus groups. We may modify this guide as needed as each focus group will inform the subsequent groups.*

Before the group begins, conduct the informed consent process, including compensation discussion.

I. Introduction (10 m)

- Welcome participants and introduce yourself.
- Explain the general purpose of the discussion and why the participants were chosen.
- Discuss the purpose and process of focus groups
- Explain the presence and purpose of recording equipment and introduce observers.
- Outline general ground rules and discussion guidelines such as the importance of everyone speaking up, talking one at a time, and being prepared for the moderator to interrupt to assure that all the topics can be covered.
- Review break schedule and where the restrooms are.
- Address the issue of confidentiality.
- Inform the group that information discussed is going to be analyzed as a whole and that participants' names will not be used in any analysis of the discussion.
- Read a protocol summary to the participants.

This study is intended to bring forth and clarify the knowledge, beliefs and attitudes towards food of Anishinabek M'Chigeeng community members with Type 2 Diabetes.

There is a significant population of Aboriginal people with diabetes in M'Chigeeng First Nation as well as on the rest of Manitoulin Island. It is believed by physicians serving Manitoulin Island patients that complications associated with diabetes develop more quickly and severely in their Aboriginal patients. This belief has been confirmed in other Aboriginal communities where Diabetes associated complications and co-morbidities such as high blood pressure, obesity, cardiovascular disease, cerebrovascular disease, end stage kidney disease, diabetic nerve damage (neuropathy) and diabetic eye disease/damage (retinopathy) occur at higher rates than expected within the Aboriginal diabetic population.

Positive lifestyle changes, including a healthy diet, are important factors in the management of diabetes. Research demonstrates the effectiveness of proper nutrition in improving diabetes control. Nutrition education, through community programs and nutrition counseling, assists community members with Type 2 Diabetes to consider lifestyle change, and for attaining the necessary skills and nutrition knowledge to manage their Diabetes. Additionally, a better understanding of cultural beliefs and attitudes towards foods may be used to improve cultural competence of Diabetes Educators.

Discussion Guidelines:

We would like the discussion to be informal, so there's no need to wait for us to call on you to respond. In fact, we encourage you to respond directly to the comments other people make. If you don't understand a question, please let us know. We are here to ask questions, listen, and make sure everyone has a chance to share.

If we seem to be stuck on a topic, we may interrupt you and if you aren't saying much, we may call on you directly. If we do this, please don't feel bad about it; it's just our way of making sure we obtain everyone's perspective and opinion is included.

Anything that you say or do in the study will not be attributed to you personally, however it will be attributable to this group. Anything that we find out about you that could identify you will not be published or told to anyone else, unless we get your permission. Your privacy will be respected. We will ask the other members of the workshop and focus groups to keep each other's identities, participation and what you say confidential, but cannot guarantee they will do so.

The information obtained will be kept in a locked filing cabinet and be only available to the investigators. The information (raw data) will be destroyed after the report is completed in _____ 20__.

We hope you'll feel free to speak openly and honestly.

As discussed, we will be tape recording the discussion, because we don't want to miss any of your comments. These tapes are treated as confidential. The information (raw data) will

be destroyed after the report is completed in _____ 20__. It will only be accessible to the research team for the purposes of completing this research. M'Chigeeng Health Services will have access to the transcribed script once identifying information, like names; have been removed for their own community based research in the future.

(If assistants present) Helping are my assistants _____ and _____. They will be taking notes and be here to assist me if I need any help.

Let's begin. Let's find out some more about each other by going around the room one at a time. Tell us your first name and _____. I'll start.

Topic: Diabetes and Diet

1) Today we are here to talk about Diabetes and food. What comes to mind when you hear "food and diabetes"?

As per focus group training for interactive process you can then: a. Take a topic that was just brought up and prompt the group for more information. b. Alternatively, you can bring up a sub-question from the list related to the main discussion question to prompt the group: (In this way, you will explore a series of questions to be followed by relevant prompts to clarify the item. This process is not pre-scripted but interactive in its nature. The goal is for the participants' experience to lead the way, therefore eliciting the most authentic data possible.) Record the key thoughts / ideas on flip chart paper for reference and give a starting point if discussion lessens.

Possible sub questions

- In your opinion is there a connection b/w food and the development of diabetes
- Once a person has diabetes what role does food play in diabetes?
- Can diabetes be controlled without taking care of the food?
- What foods do you think of managing your diabetes?

- How have your beliefs changed over time about diabetes and food as you have had diabetes longer?

Topic: Traditional Food and Diabetes

2) What role do traditional foods play in diabetes?

Possible sub questions

- What role can traditional foods play once a person has developed diabetes?
- What part or role does hunting, gathering and growing foods play in diabetes?
- How common is the use of traditional foods in M'Chigeeng ?

Topic: Cultural Gatherings, ceremonies and diabetes diet

3) How do foods or food availability at cultural gatherings fit in with your diabetes?
4) How does diabetes, diabetes diet affect you when engaging in a fast?

Possible sub questions

- What types of food are available at Cultural gatherings (Pow Wows, ceremonies, etc.)?
- How do foods at Cultural gatherings fit into diabetes?
- Is your level of blood sugar control different or the same as when not attending certain cultural gatherings?

Topic: Family

5) How does your family fit in with your diabetes and food for managing it?

Possible sub questions

- Are there any barriers for managing your diabetes with food when visiting relatives?
- How does family impact your food choices?
- What are some supporting or non-supporting actions families have on people with diabetes?
- How can people with diabetes gain their families support in your opinion?
- How does having diabetes and recommended diabetes food guidelines make you feel in your family?
-

Topic: Food Groups (selected foods / food group related questions)

6) Traditionally milk and dairy products were not a part of the traditional diet. Furthermore it is estimated that more than 70% of Aboriginal people are lactose intolerant, which means they have decreased ability to digest a type of sugar in milk which causes gas, stomach ache and sometimes diarrhoea. What role do you see milk and dairy products (yogurt, cheese) playing in your management of diabetes and that of other Aboriginal people with diabetes?

7) What role can/do legumes (dried beans, peas, lentils) play in managing diabetes in your opinion?

8) What role do Vegetarian meals play, if any, in managing diabetes ? What is your acceptance or thoughts on vegetarian meals ?

Thank participants for their time. Add that if they have any additions or wish to remove information they verbalized they can contact the primary researcher.

APPENDIX D

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Type 2 Diabetes Research Study Advertisement

SEEKING RESEARCH PARTICIPANTS
for a research study on food beliefs, attitudes and commonly consumed foods of Anishinabek community members with Type 2 Diabetes Mellitus.

There is a significant population of Anishinabek and Aboriginal people with Type 2 Diabetes on Manitoulin Island. Food is one of the important factors in the management of diabetes. Understanding yet unqualified beliefs and attitudes towards today's foods and nutrition issues may lead to practical nutrition education applications and allow for more culturally appropriate diabetes community programming. Additionally, a better understanding of cultural beliefs and attitudes towards foods may be used to improve cultural competence of Diabetes Educators and other health professionals.

The research requires 30 participants who:

5) Able to attend one 90 minute focus group session in M'Chigeeng
    - transportation may be available within the community.
6) Able to complete a 4-day self-administered Food Diary (recording the foods and drinks you have)
7) Reside in M'Chigeeng First Nation.
8) Over the age of 18 years.
9) Have been diagnosed with Type 2 Diabetes.
10) Of Anishinabek or other Aboriginal ancestry.

Participants will be reimbursed for their time.

If you would like to participate in this research project, please call (705) 368-2182 ext 233. Please leave a message with your name and contact information.

You can also send an email to zsolt.toth@noojmowin-teg.ca

Primary researcher information:
Zsolt Toth, RD, MPH (candidate)
Noojmowin Teg Health Center
48 Hillside Rd, Aundeck Omni Kaning
Little Current ONT, P0P 1K0

GLOSSARY

HbA1C - is a test that measures the amount of glycated hemoglobin in your blood. It identifies the average blood glucose level over the last 2-3 months of an individual.

Health literacy - is an individual's ability to read, understand and use healthcare information to make decisions and follow instructions for treatment.

Food security – is when all people at all times have access to sufficient, safe, nutritious food to maintain a healthy and active life". Commonly, the concept of food security is defined as including both physical and economic access to food that meets people's dietary needs as well as their food preferences.

Macro-albuminuria - Albuminuria is a pathological condition wherein albumin is present in the urine. It is a type of proteinuria. It is a sensitive indicator of kidney damage.

Member checking - In qualitative research, a member check, also known as informant feedback or respondent validation, is a technique used by researchers to help improve the accuracy, credibility, validity, and transferability (also known as applicability, external validity, or fittingness) of a study. In many member checks, the interpretation and report (or a portion of it) is given to members of the sample (informants) in order to check the authenticity of the work. Their comments serve as a check on the viability of the interpretation.

Micro-albuminuria– a condition in which the kidneys leak small amounts of protein in the urine. A highly sensitive indicator of glomerular disease and a sign that kidneys are not functioning properly.

Nutritious Food Basket - is a survey tool that is a measure of the cost of basic healthy eating that represents current nutrition recommendations and average food purchasing patterns. Food costing is used to monitor both affordability and accessibility of foods by relating the cost of the food basket to individual and family incomes (Ministry of Health Promotion, 2010).

Purposive sample - is a sample selected in a deliberative and non-random fashion to achieve a certain goal. In a focus group, for example, you may want to consciously seek out respondents at both ends of a spectrum (as well as some in the middle) to insure that all viewpoints are adequately represented. You might also preferentially recruit subjects who have the best knowledge and experience in an area.

Retinopathy - Referring to damage to the light-sensitive portion of the eye resulting from changes in blood flow due to such diseases as hypertension and diabetes.

Type 1 Diabetes Mellitus - is a form of diabetes mellitus that results from autoimmune destruction of insulin-producing beta cells of the pancreas. The subsequent lack of insulin leads to increased blood and urine glucose. The classical symptoms of polyuria (frequent urination), polydipsia (increased thirst), polyphagia (increased hunger), and weight loss result. Type 1 diabetes is fatal unless treated with insulin.