**Antecedents and Social Consequences of Type 2 Diabetes Among
Urban First Nations People, Especially Women, of Eastern
Ontario: Western Science and Indigenous Perceptions**

by

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ABSTRACT

This thesis outlines an anthropological investigation of perception and management of Type 2 Diabetes among urban First Nations People in an eastern Ontario setting. Research objectives included identifying shared social, cultural and historical circumstances which have contributed to the emergence of diabetes among First Nations People, particularly with reference to contributing factors to this disease; and finally, understanding the coping mechanisms and patterns of disease management. Similar to other areas, here also high prevalence of diabetes is linked to lack of physical activity and appropriate diet. In the contemporary urban context, explanations include poverty, food insecurity, limited access to food and physical activities. Those are being shaped by structurally violent relationship between Aboriginal people and larger Canadian social system, precipitate negative health outcome, such as Type 2 Diabetes. Diabetes is seen as a reflection of economic and social conditions, but also low self-esteem and self-worth arising from a colonial past. These perspectives have repercussions for reaction to diabetes diagnosis and coping strategies around diet, physical activity and medication. Current levels of diabetes and management strategies, including treatment, support and education meet these urban Aboriginal peoples' need only to some extent.

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Chapter 1

Introduction

This thesis offers an anthropological investigation of the antecedents and consequences of Type 2 Diabetes among urban First Nations peoples of Eastern Ontario with special reference to women. The discussion goes beyond the medical model of diabetes to create an understanding that diabetes emerged as a consequence of numerous changes in Aboriginal life resulting from colonialism and assimilation policies. Increasing prevalence of diabetes continues to be influenced by contemporary structural and economic inequalities along with the historical contingencies. At the same time, this thesis also seeks to explore the experiences of living with diabetes in an urban context from both the health care professionals' and indigenous peoples' perspectives. Primarily, it aims to investigate how urban Aboriginal peoples perceive this disease and cope with the diabetes diagnosis, and how they manage or deal with that. A special emphasis is given to women and their lived experiences. More precisely I will examine both the Western biomedical perception as well as indigenous perception of "diabetes" in terms of what diabetes is; what causes diabetes; what are the consequences of getting diabetes; and what one should do once one gets diabetes.

Rationale:

It is commonly recognized that minority groups in Canada suffer from poorer health, with health indicators such as infant and adult mortality rates steadily growing worse (Loustau and Sobo 1997: 21-48). Canadian Aboriginal people experience higher

levels of mortality and morbidity. Diabetes is an especially pervasive health problem for Aboriginal communities among other chronic diseases, which have been prominent in the last forty years. The risk of developing Type 2 Diabetes is much higher among Aboriginal than among Caucasians in North America (Haffner 1998: C3-C6). A report (Health Canada 1998: 3) based on *APS I* (Statistics Canada 1993a) reveals that Aboriginal People mostly suffer from Type 2 Diabetes Mellitus or Non-Insulin-Dependent Diabetes Mellitus, as opposed to the Insulin-Dependent-Diabetes Mellitus or Type 1 Diabetes Mellitus. Since the early 1970s diabetes has been recognized as an emerging, serious health problem among many Aboriginal communities in North America (Young 1994). *The Aboriginal Peoples Survey I* (Statistics Canada 1993a) reveals that approximately two-third of First Nations people with a diagnosis of diabetes are women. This is significantly different from the overall trend among the general Canadian population in which men and women are equally affected (Statistics Canada 1994). According to Young's 1990 review, the highest age-standardized diabetes prevalence rate was found in Canadian Aboriginal people, especially among Algonkian speaking Cree-Ojibwas of North Western Ontario, but the rates are very high among urban Eastern Ontario Aboriginal people as well. According to initial findings of the *Aboriginal Peoples Survey II* (Statistics Canada 2004) Diabetes among the non-reserve Aboriginal population was most prevalent among First Nations people (Figure 1). 8.3 % of the population age 15 and over was diagnosed with diabetes, as opposed to 6% and 2.3% of the Metis and Inuit population respectively.

Figure 1
Percentage of population with selected chronic conditions: Aboriginal
identity non-reserve population 15 years and over, 2001

Source: Aboriginal Peoples Survey II (Statistics Canada 2004).

The onset of diabetes is attributed to both genetic and environmental factors (Szathmary 1987: 42). Much of the literature on the question of onset has focused on the role of genetics in Type 2 Diabetes Mellitus or Non-Insulin-Dependent Diabetes Mellitus (NIDDM) and variations in rates between ethnic groups (Haffner 1998: C5). However currently the most plausible explanation is that the increase in rates of NIDDM among Aboriginal people is a result of lifestyle changes since World War II, coupled with genetic susceptibility (Szathmary 1987: 42). Recently a focus on the cultural knowledge surrounding diabetes has emerged. These studies (Garro 1995: 40-43; Young 1987; Joe and Young 1993: 7-14; Hagey 1984: 267-269) indicate that diabetes mellitus is understood within a particular cultural milieu and that shared social and historical circumstances have contributed to the emergence of the disease, the social consequences of disease and to the various Aboriginal understandings of diabetes.

Approaches to understanding the emergence and unique susceptibility of particular population groups to Type 2 Diabetes Mellitus are to a degree directed by the identification of the problem as an issue of ethnicity or ancestry. In the contemporary context it is therefore very significant to explore the causes and consequences of Aboriginal diabetes in a particular geographical setting, such as in Small Town, eastern Ontario¹.

Defining Diabetes Clinically:

“Diabetes mellitus is a group of metabolic disorders characterized by abnormally high levels of blood glucose secondary to inefficient insulin action and or secretion. This disease often leads to significant disability, including renal failure, blindness, and limb amputation, and to premature death” (Narayan, 1997: 169). Although many etiological classifications exist for diabetes, the two most common types are referred to as ‘Type 1 Diabetes Mellitus (T1DM)’ and ‘Type 2 Diabetes Mellitus (T2DM)’ and a third common form of the disease is Gestational Diabetes Mellitus (GDM).

In Insulin Dependent Diabetes Mellitus (IDDM) or Type 1 Diabetes Mellitus, secretion of insulin by the pancreas is severely impaired, resulting in abnormally high levels of blood glucose. Non-Insulin Dependent Diabetes Mellitus (NIDDM) or Type 2 Diabetes Mellitus is characterized by hyperglycemia and peripheral insulin resistance. Gestational Diabetes Mellitus (GDM) occurs in some females during pregnancy, who are usually at far greater risk of developing NIDDM or Type 2 Diabetes later in life (WHO 2002: Diabetes Fact Sheet).

¹ Small Town, Ontario is the pseudonym of the place where I conducted my interviews

The symptoms of diabetes may be pronounced (symptomatic), subdued or even absent (asymptomatic). In Type 1 Diabetes, the symptoms are excessive urination, thirst, weight loss and tiredness. These symptoms may be less marked in the Type 2 Diabetes, it can also happen that no early symptoms appear and the disease is only diagnosed several years after its onset, when complications are already present (WHO 2002: Diabetes Fact Sheet). Long-term health consequences of diabetes include blindness and visual disability, kidney failure, diabetic neuropathy leading to loss and damage to the limbs (WHO 2002: Diabetes Fact Sheet).

Research Interviewees:

This research involves the participation of twenty eight Aboriginal people from various local Aboriginal organizations, a community college and a hospital based health centre of Small Town, Ontario. People also participated through third party referral. In order to get perceptions regarding diabetes and, its antecedents and social consequences from both Western biomedical as well as indigenous perspectives, I have interviewed health care professionals as well as Aboriginal community people. Aboriginal community people include diabetic and non-diabetic persons. Among the Aboriginal community peoples there are a group of educated professionals, who belong to a relatively younger age group, the rest of the interviewees belong to an older age group with more limited resources. A detailed account of research interviewees is provided in Chapter 2.

Thesis Synopsis:

At the very basic level, Type 2 Diabetes Mellitus is understood as a physical manifestation of 'disease'. But in the Western biomedical sense, the term 'disease' referred to 'abnormalities in the structure and/ or function of organs, pathological states, whether or not they are culturally recognized' (Rhodes 1996: 246) and this does not completely capture the scope of analysis that follows. In recognition of the complex meaning behind the metabolic abnormality with regard to diabetes among community members, through out this thesis both the lay and professional understanding of diabetes are taken into account.

This thesis reflects my interpretations of the qualitative information about diabetes as perceived by Aboriginal people in an eastern Ontario urban setting. In the second chapter I introduce the research participants. The processes involved in developing the research project and selecting participants are also discussed. Research objectives included identifying the social, cultural and historical circumstances which have contributed to the emergence of diabetes among First Nations Peoples; exploring and analyzing the local perception of diabetes, particularly with reference to the contributing factors to this disease; and finally, understanding the coping mechanisms and patterns of disease management. The research objectives are addressed primarily by qualitative methods, the details of which are outlined.

Chapter 3 presents a discussion of health conditions among Aboriginal people in Canada and the changing socio-demographic profiles of First Nations people, as a legacy of colonialism. A survey of the existing body of research on diabetes among North

American Aboriginals, illustrating the range of work that has taken place in the last forty or so years is presented. Various understandings of diabetes in health care professional and lay arenas are summarized and this has helped to formulate the conceptual framework for analysis and interpretations of research results. Professionally, diabetes is understood as a physical sickness with links to genetics, biology and environment along with the contemporary socio-cultural and economic inequalities and historical contingencies. On the other hand, a review of lay perceptions or the indigenous understanding of diabetes indicates that diabetes also has a culturally appropriate meaning. *First Nations and Inuit Regional Health Survey (FNIRHS)* (1999: 68) explained diabetes as a chronic disease with multifactorial etiology. Therefore it is important to understand the very complex etiology and epidemiology of diabetes in great detail from both Western biomedical as well as from community peoples' perspectives.

Research results are presented in Chapter 4, which highlights various perspectives on the emergence and context of diabetes among Aboriginal people as found in the literature and life experiences of the people who participated in this research. It is clear from the interviews with people who are living in Small Town, though largely born and brought up in different parts of Canada experienced similar trends in subsistence and lifestyle changes which accompanied the emergence of diabetes. Interpretations of diabetes as a disease both at the Western scientific (health care professional) and indigenous levels (lay level) that are produced by peoples' individual life experiences are explored. At both the levels it is recognized that diabetes is entangled in a complex web of social and cultural circumstances that make its coping and management so challenging for the affected people. A discussion of formal and informal sources of support for

diabetes in this urban setting is also presented. While they are meeting some of the needs of the community people, a more comprehensive Aboriginal specific health strategy is needed.

The final chapter summarizes the significance of the research approaches for understanding diabetes among urban Aboriginal people. A discussion of limitations on this research is included. A number of avenues for future research are explored and a discussion on policy implications is outlined.

Chapter 2 Methodology

This chapter describes the methodology, the phases of the research, the research participant selection procedure, the nature of questions posed during interviews and outlines the information recorded in this research.

My research objectives were formulated around the premise that social, cultural and historical (colonial) transformation of First Nations lifestyles, particularly since the Second World War, gave rise to the current prevalence of Type 2 diabetes in the urban settings. Therefore, this research focuses on understanding the nature of these transformations and their continued influence on coping mechanisms and on patterns of health-seeking behaviour among urban Aboriginal group. Specific objectives include:

1. To identify the shared social, cultural and historical circumstances that have contributed to the emergence of diabetes among First Nations People.
2. To explore and analyze local perceptions of diabetes, particularly with reference to the factors contributing to this disease.
3. To understand the various coping mechanisms and strategies for disease management.

Qualitative research methods are the primary methods used in this research. Qualitative research is a field of inquiry in its own right. It crosscuts disciplines, fields and subject matters. There are many methods and approaches that fall under the category of qualitative research, such as interviewing, participant observation and visual methods (Denzin and Lincoln 1994: 1). The principal qualitative research methodology used in this research is the interviewing process.

According to Fontana and Frey (1994: 361), interviewing has a wide variety of forms and a multiplicity of uses. The most common type of interviewing is individual, face-to-face verbal interchange, but it also can take the form of group interviewing, mailed or self-administered questions. Interviews can be structured, semi structured, or unstructured. Structured interviewing refers to a situation in which an interviewer asks each respondent a series of preestablished questions with a limited set of response categories. There is very little flexibility in the way questions are asked or answered in a structured interview setting (Fontana and Frey 1994: 363). Another developing form of interviewing that can be implemented in a structured, semistructured or unstructured format is the group interview or systematic questioning of several interviewees simultaneously in formal or informal settings (Fontana and Frey 1994: 364). Another form of interviewing is unstructured interviewing. These kinds of interviews are based on a clear plan that the interviewers keep constantly in mind, but they are also characterized by a minimum of control over the informant's responses (Bernard 1988: 204). In semistructured interviews, the interviewer uses an interview guide that is a list of questions and topics that need to be covered in a particular order. The interviewer still maintains discretion to follow leads and this method of interviewing has much of the freewheeling quality of unstructured interviewing (Bernard 1988: 204). In this research I have followed semistructured interview method.

Interview Setting and Research Interviewees:

This study took place in an urban setting of eastern Ontario among local First Nations peoples. Fieldwork was done during the period of March, April and May 2004.

Twenty-eight people from diverse backgrounds participated in this research. All of them were able to understand and converse in English. They include eight First Nations diabetes patients, twelve First Nations community members who are not diagnosed with diabetes, four program co-ordinators from various Aboriginal organizations, one Long Term Care support worker, one nurse, one doctor, and one researcher. One of the patients was an Elder as well as a traditional healer and one of the co-ordinators was a trained nurse. All the twenty community people including eight diabetic and twelve non-diabetic persons represent lay people, whereas the rest of the eight people represent health care professionals. Twenty-three women and five men voluntarily participated in this research. All of the eight diabetes patients have Type 2 Diabetes. All these patients have been diagnosed with Type 2 Diabetes over the past one year to twenty-eight years. Tables 1 and 2 provide a summary of information on the diverse group of participants interviewed for the research.

In addition to my thesis committee members at Carleton University, I received help from members of local Aboriginal organizations in developing the thesis proposal and the list of questions around which the semi-structured interviews were conducted. Having received the approval for the proposal from my thesis committee, I applied for Carleton University's Research Ethics approval, which required a detailed project proposal, a list of questions to be asked during interviews, a letter of Information and an Informed Consent form. The Research Ethics Committee approved the research proposal with some minor changes that I incorporated later.

The selection of interviewees was done in a way that best answers the research objectives, such as consultation with researchers and program co-ordinators from Aboriginal

Table 1: Summary of information of the Lay Participants interviewed for the Research

Number	Sex	Age	Ancestry	Place of birth	Lay people		Staying in urban setting (Years)
					Aboriginal diabetes patients	Non-diabetic Aboriginal people	
1	F	77	Aboriginal	Bush	Yes	No	10
2	F	39	Aboriginal	Reserve	Yes	No	12
3	M	55	Aboriginal	Urban	Yes	No	Throughout his life
4	M	27	Aboriginal	Urban	Yes	No	Throughout his life
5	F	56	Aboriginal	Rural	Yes	No	15
6	F	52	Aboriginal	Rural reserve	Yes	No	6
7	F	68	Aboriginal	Bush	Yes	No	20
8	F	62	Aboriginal	Suburban area	Yes	No	19
9	F	74	Aboriginal	Reserve	No	Yes	36
10	F	58	Aboriginal	Reserve	No	Yes	41
11	F	39	Aboriginal	Urban	No	Yes	Throughout her life
12	F	65	Aboriginal	Reserve	No	Yes	29
13	F	24	Aboriginal	Urban	No	Yes	5
14	M	45	Aboriginal	Reserve	No	Yes	5
15	F	21	Aboriginal	Reserve	No		Commute to urban area for work everyday
16	F	27	Aboriginal	Reserve	No	Yes	5
17	F	46	Aboriginal	Bush	No	Yes	3
18	F	42	Aboriginal	Reserve	No	Yes	4
19	F	44	Aboriginal	Suburban area	No	Yes	4
20	F	45	Aboriginal	Reserve	No	Yes	17

Note: N/A= does not apply, N/K=not known

Table 2: Summary of Information of the Health care professionals interviewed for the Research

Number	Sex	Age	Ancestry	Place of birth	Diabetes patients	Health care professionals or researcher	Staying in Urban setting (Years)
1	F	N/K	Aboriginal	N/A	No	Yes	N/A
2	M	N/K	Non-Aboriginal	N/A	No	Yes	N/A
3	M	N/K	Aboriginal	N/A	No	Yes	N/A
4	F	N/K	Non-Aboriginal	N/A	No	Yes	N/A
5	F	N/K	Aboriginal	N/A	No	Yes	N/A
6	F	N/K	Aboriginal	N/A	No	Yes	N/A
7	F	N/K	Aboriginal	N/A	No	Yes	N/A
8	F	N/K	Aboriginal	N/A	No	Yes	N/A

Note: N/A= does not apply, N/K=not known

organizations in and around the study locality. The interviewees include clients and staff members from three local Aboriginal organizations and a community college. Some were selected through additional contacts and cross referrals. The objective of capturing such a wide range of participants was to get a broader view of diabetes perceptions from different perspectives. For example, it is worth gathering the opinions of organizations that had been actively working with the Aboriginal people to get a picture at a community level and their practical experiences of working with the community.

Once ethics approval had been received from Carleton University's Research Ethics Committee, I then negotiated access to the study community; this involved several steps. First of all, I identified potential Aboriginal organizations in the locality that might be important to approach for research participation. Then I approached these Aboriginal organizations with my research plan and got a mixed response. Some of them did not want to proceed in terms of research participation. Some asked me to give them a talk on the research project; some forwarded my e-mails with a 'letter of information' to staff members

in their employ. These organizations helped me to get in touch with those expressing an interest. I was also able to get in touch with a few interviewees through third party referral. One program co-ordinator put me in touch with a diabetes patient who was also an Aboriginal Elder as well as a traditional healer. I came in contact with a nurse through a referral by a doctor who has a long experience of working with Aboriginal patients. After initial contacts, thirty people voluntarily agreed to participate. Finally I was actually able to interview twenty-eight people. Two of them withdrew from the interview due to personal reasons.

The in-depth semi-structured interviews were conducted at a time and place convenient to the research participant on a one-to-one basis. The actual time of the interview was made amenable to the respondent. The earliest interview was conducted at 9:00 a.m. in the morning, the latest interview started at 7: 00 p.m. in the evening. The actual length of interviews ranged from as short as fifteen minutes to as long as two and half hours. The average time taken for an interview was about an hour. Before starting the interviews, each participant was requested to go through the informed consent and to give the researcher permission for the interview. One person was not able to read the form, so it was read to her by the researcher. Interviewees were made aware that they did not have to answer any questions they are uncomfortable with, and that they could withdraw at any time although the researcher could use any given information up to that point. All except two (who did not want to be recorded) interviews were tape-recorded with the interviewee's consent.

Times of interviews were scheduled based on the availability of the respondents. Initially, contact was made with the participants by the researcher to ensure consistency in the initial contacts. If the interview time was set up more than a few days in advance, the

potential research participant was usually contacted the day before, or the day of the interview to confirm the time and date. At some organizations interviews were scheduled by the office manager and the researcher was informed of the interview time. As suggested by Lofland and Lofland (1984: 24) it is always important that interview sites are appropriate and that the interview take place where the research participants are comfortable and there were few interruptions (Neuman 1991). Interviews with the staff members of Aboriginal organizations and a few students of a local community college were conducted inside a closed-door office space. Interviews with some diabetic as well as non-diabetic Aboriginal people were held in the respondent's homes. They seemed to be at ease within their comfortable settings and this apparently helped to ease some of the tension that was created by partaking in the interviews.

Interviews with health care providers took place at their offices. Various other places were also used as interview sites – a hotel dining room, a healing lodge and a quiet moment in between the presentation sessions of a national conference.

Some of the key interviews were transcribed word for word, and the rest of the interviews were transcribed verbatim where I have transcribed selective segments of the interview conversation. As emphasized in Lofland and Lofland (1984) and in Schatzman and Strauss (1973), the post-interview reports, field notes and a summary of the conversation were written up as soon as possible after the interview. To maintain anonymity and confidentiality, code numbers and pseudonyms were used to identify all audiotapes and interview transcripts². Only the researcher had access to the master list of code

² In order to protect anonymity and confidentiality real name of the research participants are not disclosed in this thesis, only pseudonyms are used. Geographical location of the research area is also protected. Small Town, Ontario is a pseudonym of the research locality.

numbers/pseudonyms and participant's real names. Apart from the researcher, only her thesis committee members had access to the interview transcripts. All the research materials were kept in a locked secure filing cabinet indefinitely for the researcher's purpose for future academic work.

Interview Process: Questions Posed

The nature of the questions pursued during the interviews varied somewhat depending upon the category of interviewee. For example, questions to non-diabetic participants concentrated more on their experiences in dealing with diabetic members of the family and friends. For respondents' better understanding sometimes questions were broken into shorter forms or reworded.

Interviews with diabetic and non-diabetic First Nations interviewees:

All interviews were as loosely structured as possible, in the hope that the discussion would develop as much as possible along the lines of a relaxed conversation. I did not use any structured questionnaire. However lists of questions relevant to the background of the interviewees were developed to facilitate the conversation. Not all the questions in the list were asked of all the respondents. Some additional questions were also asked if it seemed suitable to the flow of conversation and relevant to the study. The respondents were not asked any direct demographic questions except questions regarding their age and duration of residence in urban setting, but their basic characteristics such as economic condition, source of income etc. were assessed indirectly from some of their answers. At the end of each

interview, the participants were asked if they had anything else to add to the discussion. This gave a chance for their own input if there was some topic that they thought had been missed.

The first section of the lists of questions for diabetic and non-diabetic First Nations participants was aimed at recording general life stories. A second, more structured section contained specific questions about diabetes³. Examples of questions designed to obtain information about diabetes included— “In your opinion what causes diabetes? Please explain your understanding of diabetes?” These questions were aimed to investigate the interviewee’s understanding of the social, cultural and historical circumstances that have contributed to the appearance of diabetes. It also helped to know how they interpreted diabetes, or what comes to their mind when they utter the word ‘diabetes’.

In an aim to explore the life experiences of diabetes patients and community members, interviewees were asked the following questions— “How did you react when you found out that you have this disease? What do you think is the most difficult thing for people living with diabetes?” Questions were also asked that are relevant to coping mechanisms and disease management in order to understand the phases of life experiences they are going through since they are diagnosed with the disease and what kind of treatment strategies they are adopting. In this respect, it is very much relevant to know non- diabetic community members perspectives, because they also encounter incidences of everyday struggle that their family members or community members are going through after their diagnosis—“Do you think that diabetes interferes in family and social relations? If so, how does it take place? How are people dealing with that? As a woman are you concerned about anything in particular (if the participant is woman)? What are the kinds of activities you do to try to

³ Throughout this thesis Type 2 Diabetes and Diabetes is used interchangeably.

manage diabetes? Other than the doctor, upon whom do you depend for your treatment? How much do you think the things you do help to deal with the disease?"

Interviews with health care providers, program co-ordinators, and researcher:

While talking to health care providers, my particular concern was to capture various perceptions of the issues related to diabetes appearance among urban First Nations people and their experiences in implementing education, prevention and treatment initiatives. Examples of questions regarding these issues included— "Why do you think diabetes is a problem among First Nations people in an urban context? What do you think are the significant social, cultural and historical processes that place First Nations people at risk of becoming chronically ill? What do you think are the most effective strategies for diabetes management among First Nations people? What are the kinds of frustrations urban diabetics faces in trying to live a healthy lifestyle? What do you think are the most effective public health measures for dealing with diabetes in First Nation communities? How do you envision the future of health promotion in urban areas?" As in interviewing the community members, here also I chose to follow semi-structured or loosely structured interviews, allowing the flow of the conversation to suggest additional questions and directions. At the end of the each interview, interviewees were asked for any additional comments they might have in order to fill in any gaps during conversation if there were any.

Qualitative Analysis:

The conceptual framework that I developed (in Chapter 3) has helped to analyze and understand the diabetes experience among urban First Nations people. During the course of formal or informal conversations, the respondents brought up a number of issues that were integrated under several broader themes. In examining the semi-structured or loosely structured interviews, themes were analyzed to determine where diabetes fits into the life experiences of interviewees of different ages and those with or without diabetes. A particular emphasis was placed on understanding and analyzing First Nations women's views regarding diabetes and its management. In comparing the life experiences of diabetes patients with what health care professionals and health care providers told me, the goal was to identify areas of similarity in perception, as well as gaps and misconceptions. Some analysis also was devoted to various means for the delivery of diabetes education, prevention treatment initiatives, and how these meets the needs and perceptions identified by the interviewees. A particular focus was placed on what First Nations people thought to have contributed to their diabetes and how are they coping or managing with it.

Chapter 3

Review of the Literature

The primary aim of this chapter is to present a review of diabetes research among North American Aboriginal populations that was carried out in the field of medical science, population health and social science. Here I examine a sample of research that I have come to know about Type 2 Diabetes as a disease, and its prevalence, magnitude and perception about management in the context of Aboriginal people from a vast and diverse literature. This review helped me to formulate the conceptual framework for my research and to shape my interpretations of the perception of diabetes, coping mechanisms and strategies for management among urban First Nations peoples of Small Town, Ontario with special reference to urban women.

Before beginning the review of the literature and its relevance to North American Aboriginal population, a discussion of the present health conditions among Aboriginal people in Canada and the changing socio-demographic profiles of First Nations peoples, as a legacy of colonization is presented.

Changing profiles of First Nations People: The Impacts of Colonization

The Status of Aboriginal Health in Canada:

Aboriginal people⁴ in Canada suffer enormous inequities in health compared to general Canadian population -- ranging from a high infant mortality rate to high rates of

⁴ In Canada 'indigenous populations' refer to a set of three distinct Aboriginal population groups, namely, First Nations (formerly, Native or Indians), Inuit (formerly Eskimos) and Métis (biological descendants of First Nations and French or European ancestors). Most indigenous people in Canada now prefer the term 'Aboriginal' considering it less derogatory than 'Native' or 'Indian'. Throughout this thesis wherever

injuries, infectious diseases, and an epidemic burden of chronic diseases. The root of the inequities in Aboriginal health is interwoven with the history of European contact; the importance of natural resources and geography over time; politics; economics; and their impacts on cultural or social change (Canadian Medical Association 1994: 21). European contact and colonization, though not solely responsible for deteriorating health conditions, advanced the destruction of Indian self-sufficiency through the process of primitive accumulation and eventual transition towards advanced industrial capitalism (Satzewich and Wotherspoon 1993: 151). Many Aboriginal people feel angry and frustrated, stemming from the feeling of powerlessness that has derived from the fact of colonization. O' Neil (1986: 250) offers 'internal colonialism' as a conceptual framework for the evaluation of health effects in the North American context. This concept of internal colonialism is centered on power relations, especially in a situation, where one ethnic group is dominated by another (e.g. politically, economically, culturally, and spiritually). Here, the source of distress is not the process of change, but rather dominant political and economic structures that limit individual and population endeavors to construct meaningful and rewarding socio-cultural environments.

Power is the fundamental driving force behind any individual's or community's ability to maintain their health. To maintain health, one must have power, especially economic power to ensure reasonably secure life conditions. Author such as George Manuel (1970) explained how Canadian Aboriginal people have historically faced oppression, segregation (reserves) and assimilation through removal of their children (residential schools) by dominant powers. Genocide of the Native peoples (which has

collective reference is necessary I use the term 'Aboriginal People' except when referring to other authors' work

been and still is a serious global activity) was effortlessly mixed with subjugation (the colonialism that robs the oppressed even of their language and identity). In his search to find the answer why and how these two things (genocide and subjugation) happened, George Manuel (1970: 214) coined the term 'Fourth World'. Manuel took the concept of pan-Indianism and opened this concept to the whole world, seeing the necessity of decolonization. But he also envisioned the possibility of a re-rooting of traditional knowledge and being, from which indigenous peoples could move forward to a place where a rebirth of indigenous self-confidence is possible. As we mentioned earlier the unequal power relations between the two ethnic groups fail to construct meaningful and rewarding socio-cultural environment, thus create a structurally violent relationship with one another. Farmer (1999: 1486) in his paper, 'Pathologies of Power' stresses that most human rights violators are embedded in "structural violence" — social and economic inequalities that predict who are likely to be at risk for assaults and who will be shielded.

The concept of "structural violence" was developed by the Norwegian peace researcher Johan Galtung in connection with unjust feudal systems, unequal power relationships, and the unequal chances of life for the people concerned. According to Galtung (1980: 67-68, 107-112), structural violence exists when people are prevented from developing (in body and in mind) in the social system in which they find themselves. The violence is built into the structure, usually derived from some fundamental inequity that then generates and is reinforced by, inequality and injustice. In contrast to personal violence, which can be attributed to actual people, structural violence functions anonymously and is intangible. Its sociocultural sources are intangible or not clearly visible and located in the immediate social context. Structural violence is easily

perceived in its varied net effects, such as uneven resource distribution; unequal access to medical supplies, hygiene, education, income; and so on. Along with these living conditions, high mortality rates and health problems are the added features of structural violence suffered by many Aboriginal people. Therefore, it can be said that Aboriginal health is the outcome of sociocultural, economical, and political structural relations between Aboriginal people and larger Canadian social system, and the net effect of which is structurally violent. It is also said that Aboriginal women and children are at more risk of becoming victims of structural violence and sufferings. In addition, Aboriginal people who live in urban areas are more likely to be victims of violent crime than people who live in rural areas (Beavis *et al* 1997: 9-13).

After the relocation of Aboriginal population into reserves, their social and economic structures were incapable of supporting a growing population. As Aboriginal population continued to increase because of high fertility and low mortality rates and because of changes in morbidity patterns (the demographic and epidemiological transition, discussed later in this chapter) during the period of 1960 and onward, greater demand on scarce resources emerged (Frideres 1993: 259). Many reserves were not able to provide their residents with satisfactory standards of living because of the depletion of their resources, their restricted size, or because of the rising expectations among Aboriginal peoples. Unemployment was high and there was very little alternative form of work for them. This indicates that economic reasons appear to be one of the prime factors that drew Aboriginal people toward the city (Nagler 1973: 10, Frideres 1993: 259). After World War II, the Canadian economy was quickly transformed into an industrialized, urban economy from a rural, agriculturally based economy. As a result of this profound

transition, Aboriginal people found themselves migrating to urban centers in larger numbers than before. By 1960, about fifteen percent of the Aboriginal people had moved to urban areas, and this trend continued to show an upward rise (Frideres 1993: 259).

Recent census data show slow, but steady, growth among Aboriginal people residing in the nation's cities. In 2001, almost one-half (49%) of the population who identified themselves as Aboriginal lived in urban areas, which is up by 2 percentage points from 1996 (Figure 2). At the same time, the proportion of Aboriginal people living in Indian reserves and settlements declined from 33% to 31%.⁵

As per the 2001 census, less than one-half (47%) of the First Nation people (reported as North American Indian in 2001 census), lived on an Indian reserve in 2001. The majority lived in either urban centres or in rural off-reserve locations. Of the total of 632375 First Nations people, 24% lived in one of 27 census metropolitan areas (CMAs). The CMA of Winnipeg had the largest First Nations population, (22,955), followed by Vancouver (22,700), Edmonton (18,260), Toronto (13,785) and Saskatoon (11,290).⁶ The 2001 census also shows that the percentage of First Nations people living in the urban census metropolitan areas increased between 1996 and 2001 by more than 1 percentage point (Figure 3).

Aboriginal women are more likely to live in large cities than are Aboriginal men, and Aboriginal lone parent families are more common in cities than in rural areas or on reserves (Hull 2001: 4)). In a study of migration patterns based on the *Aboriginal Peoples Survey I*, it was shown that in cities in eastern and central Canada, more than 30% of in-

⁵ These data have been adjusted for incomplete enumeration on Indian reserves in 1996 and 2001. see Statistics Canada Website:
<http://www12.statcan.ca/english/census01/products/analytic/companion/abor/canada.cfm#6>

⁶ <http://www12.statcan.ca/english/census01/products/analytic/companion/abor/groups1.cfm#4>

Figure 2
Aboriginal Population by Area of Residence, Canada, 1996 and 2001

Source: Adapted from Statistics Canada website (accessed on August 21, 2004 (<http://www12.statcan.ca/english/census01/products/analytic/companion/abor/groups1.cfm#6>)).

Figure 3
First Nations Population by Area of Residence, Canada, 1996 and 2001

Source: Adapted from Statistics Canada website (accessed on August 21, 2004 (<http://www12.statcan.ca/english/census01/products/analytic/companion/abor/groups1.cfm#4>)).

migrant families were lone-parent families (Clatworthy 1995: 247-254). Another study based on 1991 census data, found that among the Aboriginal population, female lone parents made up 15% of the total population of adult women, compared with 7% among all Canadian women (Lindsay 1992). Single mother families or female lone-parent families, particularly those living in urban settings, are especially likely to have higher levels of poverty and lower family incomes, lower educational levels, poorer health conditions, and higher levels of housing needs (Hull 2001: 1).

Along with these factors, stress, isolation, social exclusion and the effects of alcoholism place these disadvantaged groups of people at a greater risk of illness. Poor social and economic circumstances affect health throughout (WHO 2000: 10). Among Aboriginal communities, generations of people are suffering from anxiety, insecurity, low self-esteem, social isolation, and lack of control over work and home life. Such psychosocial risks accumulated during the life course are damaging in whatever area of life they arise. In the urban setting, poverty, unemployment and homelessness lead to worse health and increased risks of premature death. These include depression, increased susceptibility to infection, diabetes, and high blood pressure and stroke (WHO 2000 16-17).

Socio-Demographic Profiles of Aboriginal Health:

One of the important facts in the post-contact history of North America is that European contact precipitated a catastrophic drop in the size of Aboriginal populations (Waldram *et al* 1995: 43). The extinction of many indigenous peoples is a matter of historical fact resulting from a series of sociopolitical, economic and ecological changes.

These changes, either alone or in combination, affected the population size and demographic structure of Aboriginal populations differentially over the North America. The introduction of new pathogens and lack of immunity in combination with ecological disruption, and subversion of the social order resulted in the demographic decline through a series of epidemics among the Native Aboriginal peoples (Dobyns 1983, 1984; Crosby 1986: 196)). In this regard Thorton (1987:44) states that, “without doubt, the single most important factor in American Indian population decline was an increased death rate due to diseases introduced from the Eastern hemisphere.” An alternative interpretation of Native American historical demography suggests that population did not decrease continuously from the time of contact but declined later in combination with Aboriginal-European interaction that resulted in dramatic socio-demographic change (Mooney 1928; Kroeber 1934; cited in Waldram *et al*1995: 46).

According to Ponting (1997: 78), demographic characteristics and trends of the Aboriginal population in North America are not completely homogeneous. They differ not only in size and distribution, but also in other aspects such as their level of fertility, mortality and morbidity patterns of sickness and health. Among the Aboriginal population, First Nations peoples in Canada have experienced three phases of demographic transition: First, a prolonged era (prior to the 1950s) of high birth rates and high death rates, followed by b) a brief period (1950-1960s) of rapidly declining death rates accompanied by continuing high birth rates and finally a contemporary period of comparatively low fertility and low mortality. This demographic transition ensures longer life expectancy due to invention of modern medicine, immunization and rapid westernization.

From the end of the Second World War, most infectious diseases, such as measles, rubella, mumps, tetanus, diphtheria and tuberculosis (of Aboriginal people) were brought under control, though many infectious diseases remain at a persistently higher level than for the rest of the Canadian population. Aboriginal peoples were having an incidence of infectious disease as much as ten times higher than the non-Aboriginal Canadians (Waldram *et al* 1995: 66, 75). Concurrently, there has been a shift to diseases such as heart disease, diabetes, hypertension and obesity as the ‘disease of affluence’. The change in disease patterns was described by Omran (1971) as epidemiological transition. Epidemiological transition accounts for declining rates of communicable diseases (CDs), but increasing rates of chronic noncommunicable diseases or NCDs (such as diabetes mellitus). Young (1988: 660-670) tested the idea of epidemiological transition by using health information from Canadian First Nations population and found some of the demographic and epidemiological trends predicted by Omran (1971: 509-536), such as a reduction in the prevalence of infectious diseases associated with malnutrition, unhygienic conditions and poor environmental sanitation to a pattern of high prevalence of chronic diseases, like diabetes mellitus, cancer, heart disease etc associated with an urban-industrial lifestyle including changes in physical inactivity, stress and diet. We can trace the roots of this transition back to changes which have been taking place in the socio-cultural environment from Pre World War II period.

As mentioned earlier, over the past few decades the predominant role of infectious diseases as causes of mortality and morbidity among Aboriginal peoples has been over taken by chronic, non-communicable diseases and by accidents and violence. Of all the chronic diseases, diabetes – more particularly Type 2 Diabetes has achieved

particular prominence because of its higher and increasing prevalence among most Aboriginal groups (Waldram *et al* 1995: 87).

Because all Canadian Aboriginal population groups are not equally well represented in surveys and studies, even after 1950s and later, when the delivery of health care to Aboriginal peoples was greatly expanded and the collection of health statistics much improved, the construction of a health history of Aboriginal people remains a difficult task. Least is known about non-status Indians and Metis, particularly those living off-reserve and in urban areas (Waldram *et al* 1995: 66).

To date, the *Aboriginal Peoples Survey I* or (*APS I*) conducted in 1991 is the most comprehensive national survey of Aboriginal peoples with a significant health and social component (only the initial findings of *Aboriginal Peoples Survey II* are made available to the public). It included not only Indians on and off-reserve, and Inuit, but also, for the first time, Metis. An idea of diabetes prevalence among First Nations people by age group can be obtained from the *Aboriginal Peoples Survey I (APS I)* (Statistics Canada 1993a) (Figure 4).

The incidence of diabetes increases with age and the prevalence of diabetes is considerably higher among the Aboriginal population than average Canadian. Initial findings from the 2001 Aboriginal Peoples Survey indicate that 7% of the Aboriginal non-reserve population reported diabetes, compared with 4.3% of the total Canadian population. Further details are given in Figure 5.

Figure 4

**Diabetes by age group: Aboriginal Peoples Survey I
(percentage with diabetes)**

Source: Statistics Canada (1993a) and 1994-95 National Population Survey.

Figure 5

Percentage of Population Diagnosed with Diabetes, Canada, 2001

Source: <http://www.statcan.ca/English/freepub/89-589-XIE/health.htm> (Statistics Canada, Aboriginal Peoples Survey, 2001 and Canadian Community Health Survey 2000-01).

Geographical distribution: Urban-rural and on-off reserve distribution:

The *APS I* (Statistics Canada 1993a) data suggest that diabetes rates are lowest in the north and west of Canada, and highest in the Ontario-Manitoba-Saskatchewan area. A result of an earlier study (Young *et al* 1990: 133-135) showed that strongest predictor of variation in diabetes prevalence among Aboriginals was latitude, with increasing prevalence from north to south.

A Health Canada report (1998: 8) based on *APS I* (Statistics Canada 1993a) produced countrywide data on diabetes for people living on and off reserve. A surprising finding was that rates of diabetes are significantly higher among people living on-reserve than off-reserve, 8.4% and 5.7% respectively (Figure 6). In this case, the higher prevalence rate on reserves could be due to the maximum concentration of elderly people in those areas (Statistics Canada 1993a). A similar pattern is seen when comparing rural to urban areas. This report (Health Canada 1998: 8) also shows that Diabetes rates are significantly higher among people living in rural areas and on reserves, as compared to those urban and large cities (rural- 8.1%, urban- 5.3%). These results are contradictory to most researchers' belief that higher rates of diabetes mellitus are associated with a more 'western' lifestyle and increased urbanization. These results are also contradictory to Young's 1990 survey, in which higher diabetes prevalence was found among Aboriginal people living in urban areas compared to rural areas. These findings indicate that further investigation in terms of diabetes risk factors in urban-rural communities is required.

Figure 6
Diabetes by Area of Residence: 1991
(Percentage of First nations People with Diabetes)

Source: Aboriginal Peoples Survey I (Statistics Canada 1993a).

Income and education and gender dimensions:

People with diabetes tend to have lower income and lower education levels than non-diabetics, a finding that is partially related to the older age and gender of most people with diabetes. In contrast to the *APS I* (Statistics Canada 1993a) survey, in which 6.6% of persons identifying as Indians reported having diabetes, Statistics Canada's General Social Survey (1993b: 165) found that only 4% of the total Canadian adult population reported having diabetes. A significant increase in prevalence rates found within First Nations in rural areas, rates also increase from north to south and west to east of Canada. This pattern tend to reflect both of genetic differences within the First Nation population and the degree of isolation (Muir, 1991: 35).

Gender Inequality in terms of Diabetes Prevalence:

Early Aboriginal hunting-gathering patterns of subsistence involved high-energy expenditure irrespective of sex. 'Women the gatherer' appear to be engaged in activities that would involve high-energy expenditure such as food gathering, child rearing and domestic chores. In some hunting-gathering societies both men and women used to share food-gathering and child-rearing responsibilities, so that both sexes got adequate exercise (Eaton 1977). Since women used to gather at least fifty percent (and often more) of the food consumed, they leave the band as often as the men to obtain food. Thus there was hardly any variation between men and women in terms of energy expenditure. When their subsistence pattern changed from a nomadic to sedentary lifestyle, a dramatic change occurred with respect to women's energy expenditure. Women tend to contribute less to food gathering and took disproportionately more responsibility for household work such as child rearing and in house food production that involved less energy expenditure. The sexual egalitarianism in terms of labour thus got lost, as male versus female roles are more strongly defined in subsequent phases. Thus, aboriginal women are facing more problems with increasing rate of obesity (especially fat composition) as a result of switching from earlier, almost similar level with men, to now less energy expenditure.

Obesity is a significant health problem among Aboriginal Peoples, especially among women. The prevalence of obesity in terms of Body Mass Index (BMI) ranges from 50% to 70% in women and 30% to 50% among men (McIntyre 1986). The pattern of obesity seen in Aboriginals is predominantly abdominal, which is usually associated with impaired glucose tolerance and hypertension, thus increasing risk factors for diabetes mellitus among women. The Dion Stout *et al's* (2001: 17) work has identified

high a incidence of depression among certain groups of Aboriginal women (Dion Stout 1995), socio-economic marginalization (Ship and Norton 2000: 69-85) and finally their susceptibility to obesity (Martin and Bell 1991: 433-435; Evers 1991: 731-734) as high risk factors for diabetes prevalence among Aboriginal women.

As we mentioned earlier, a report (Health Canada 1998: 7) based on *APS I* (Statistics Canada 1993a) reveals that about two-thirds of First Nations Peoples with diabetes are women. The prevalence rate among men is 5.3%, while for women it is 7.65%. This gender difference is not observed in the Canadian population as a whole, in which 3.1% of men and 3% of women are affected by diabetes (Statistics Canada 1994). The higher rate of diabetes prevalence among Aboriginal women is observed in all age groups, although there is a possibility that some of the differences could be caused by Gestational Diabetes Mellitus or GDM (Statistics Canada 1993a) (clinical definition of diabetes explained in Chapter 1).

Type 2 Diabetes mellitus among North American Aboriginal Peoples

Type 2 Diabetes or Non-Insulin Dependent Diabetes Mellitus (NIDDM) is devastating the health and contributing to the early death of many indigenous people all over the world (Joe and Young 1993: 1). Because Type 2 Diabetes has affected greater numbers of people of non-European descent who have adopted or have become acculturated to western culture, diabetes for these people has been described as the “price of civilization” by a number of researchers (West 1974: 842; Eaton 1977: 41-42; Hagey and Bulls 1983: 29; Stern *et al.* 1983: 273). As mentioned by Joe and Young (1993: 1) high prevalence rates of Type 2 diabetes have been observed among Australian

Aborigines (O' Dea 1984); the Maoris of New Zealand (Prior and Tasman-Jones 1981); Polynesians and Micronesians (Zimmet *et al.* 1990); Mexican Americans (Gardener *et al.* 1984); and various ethnic groups in India (Gupta, Dave and Joshi 1978).

During the early part of the twentieth century diabetes was thought to occur rarely among North American Aborigines (Young 1993a: 28). The great pioneer in diabetes research, Dr. Elliot Joslin, found only 24 cases among Pima Indians when he conducted a survey prior to 1940 (Joslin 1940). By a decade later, diabetes was found among many tribes and by 1970s, it had become an epidemic (West 1974: 842-843). According to West (1974: 842), diabetes is a relatively new phenomenon among North American Natives, as it is among many other indigenous populations.

It is not entirely clear why the frequency of diabetes incidence has increased among North American Aborigines, and this demands considerable research attention. Though it is reasonable to conjecture a genetic predisposition to NIDDM, the role of environmental determinants is of undoubted importance in explaining the dramatic increase in rates of NIDDM among native populations (West: 1974: 841; Knowler & Narayan 1994: 702; Szathmary 1994: 463, 470; Knowler *et al* 1995: 485-487). Many of the known environmental determinants are potentially modifiable and offer immediate prospects for preventing or postponing NIDDM (Knowler *et al* 1995: 485-487).

With a view to better understanding the nature of the Type 2 Diabetes epidemic in North American Aboriginal context, I now review the magnitude of the problem of NIDDM among North American Aboriginal populations, more precisely in Canada and United States, summarizing the current knowledge about the determinants of NIDDM and discussing the Etiology, Epidemiology and complications of Diabetes mellitus.

Epidemiology of Diabetes mellitus:

Dr. Kelly West, father of diabetes epidemiology, carried out an extensive literature review (West 1974: 841-855) on diabetes among North American Native people as well as many indigenous people in other parts of the world. Since then, the problem of diabetes has received the attention of many scholars. Although Diabetes prevalence in the North American Native context was described as epidemic (West 1974: 842-843), until 1979, due to the absence of uniform diagnostic criteria (National Diabetes Data Group 1979, Canada; Ad Hoc Committee on Diagnostic Criteria, 1982: 473-476), it was difficult to verify this claim (Szathmary 1994: 458). As mentioned earlier (West 1974; Young 1993b) prior to 1940, this disease was virtually unknown among Native Americans. By the 1960s, the incidence of diabetes rose significantly among the Pima (Parks and Wascow 1961: 103) and the prevalence among the Cherokee of North Carolina was reported to exceed 25% among the adults older than 30 years of age (Stein *et al* 1965: 843, 844). High rates of diabetes or glucose intolerance among particular groups of Native Americans continued to appear in the medical literature throughout the 1960s (Niswander 1968; Doeblin *et al* 1969). By the 1980s, among properly diagnosed American Indian, Eskimo, and Aleut diabetes outpatients, 98% suffered from Type 2 diabetes. Evidence showed that diabetes was extraordinarily common among some tribal groups and some regions of United States, but overall diabetes prevalence was lower than the national average (2.47% in 1980). However, by 1986, the NIDDM rate in one Navajo community exceeded the United States national average (Hall *et al* 1991: 121).

Canadian Aboriginal People:

Literature on the incidence, prevalence and magnitude of diabetes mellitus among North American Native populations mostly refer to the United States. Statistical data showing time trends in diabetes prevalence are not available for Canadian Aboriginal Peoples, since the collection of baseline data started only recently (Young 1993a: 28). The observation by West (1974) that diabetes was unknown among North American Natives prior to 1940s was however, supported by Young (1993: 28), giving specific reference to the clinical examinations carried out by Chase (1937, cited in Young 1993a: 28) and Urquahrt (1935, cited in Young 1993a: 28). Szathmary's (1990) review was among the first to include some Canadian data. In her survey, she indicated the presence of hyperglycemia⁷, but little or no clinically diagnosed diabetes in northern Canadian Native and Inuit populations during the late 1960s and throughout the 1970s. In 1990, Young *et al* carried out the first attempt to determine the prevalence of diabetes among Canadian Aboriginal people. In this study, they classified groups by longitude, latitude, geographic isolation, language family membership and culture area. An ecologic analysis was performed with the crude prevalence of individual communities regressed upon independent variables like longitude, latitude, geographical isolation, language family membership and culture area. The highest rate was found in Atlantic Canada (8.7%), followed by Ontario (7.6%), and the rate decreased moving westward and especially northward. Within each region, rates are generally higher for females. In terms of geographical isolation, the rates overall were highest for urban Native peoples and lowest for those in remote areas.

⁷ Hyperglycemia: high glucose in blood

Szathmary (1994: 460) and others (Young 1993a: 21-40) described the epidemiology of diabetes among Canadian Aboriginal people as resembling that of Aboriginal people in the United States, with two notable differences. First of all, the rise in the frequency of diabetes among Aboriginal people in Canada became prominent only in last 15 years and secondly, considerable variability exists in tribal and regional prevalence rates (Szathmary 1994: 460)

The majority of Native Canadian diabetics developed their disease after 1980 (Young 1993a: 28), even allowing for changes in the availability of, and accessibility to, health services. Since then, the prevalence and incidence of this disease has continued to increase among Aboriginal groups. Contrary to the previous incidences of adult-onset of Type 2 Diabetes, nowadays an earlier-onset of Type 2 Diabetes has been increasing in young adults, particularly among Native Americans and Canadian First Nations communities (Fagot and Campagna 2000: 668; WHO 2002: Diabetes Fact Sheet). As mentioned earlier, the rate of diabetes prevalence among Aboriginal people in Canada is higher than the national average.

Epidemiological literature reporting high levels of diabetes prevalence among North American Aboriginals has led many researchers to seek explanations for these observed trends. In early epidemiological reviews (e.g. West 1974: 852), it was speculated that genetic factors might play an important role in inter-tribal differences in the prevalence and manifestations of diabetes, but environmental factors also had a powerful effect. According to West (1974: 841), studies on the emergence of diabetes among Aboriginal groups can provide a better understanding of genetic and

environmental factors, which determines the susceptibility to, and pathophysiology of, diabetes.

Etiology of Type 2 diabetes:

The etiology of Type 2 diabetes combines both the genetic and environmental factors in its onset (Ferrel and Jyengar 1993: 417-423). Populations may vary in the genes encoded at the genetic loci involved with the specific mechanisms producing the pathophysiology of Type 2 Diabetes. Some of the genes may constitute the hypothesized susceptibility genes that lead to population differences in Type 2 Diabetes morbidity (Ferrel and Jyengar 1993: 417-423). Nutrition provides the input for carbohydrate metabolism, which is in turn governed by human culture, and so the environmental involvement in Type 2 Diabetes has long been recognized. Cultural variables also influence human energy expenditure. Therefore, these two environmental phenomena are commonly placed by diabetes researchers under lifestyle related determinants (Szathmary 1994: 463). Several authors (Joe and Young 1993, Knowler *et al* 1983; Szathmary 1987) explained the current burden of Type 2 Diabetes among Aboriginal people partly as the result of lifestyle changes such as changes in diet, physical activity, and acculturation stress since Second World War that favoured the emergence of Type 2 diabetes in genetically predisposed individuals.

Biological Basis: Genetic involvement in Type 2 Diabetes mellitus

Szathmary (1987, 1994) conducted comprehensive reviews of the evidence for the genetic factors involved with the onset of Type 2 diabetes among Aboriginal populations following West's (1974) proposition on the role of genetics and environment in NIDDM.

Numerous studies reviewed by Szathmary (1994) provide evidence of genetic controls of various aspects of glucose metabolism. Other studies also suggest a major gene effect (Hegele *et al* 1999), indicate autosomal dominant (Yamashita *et al* 1984) or autosomal recessive (Elston *et al* 1974) modes of inheritance, codominant inheritance (Bogardus *et al* 1989) or the action multiple genes (Hegele 1999) coupled with an intergenerational environmental effect (Szathmary 1985). However, knowledge concerning the genetics of NIDDM is still rudimentary and more research is needed to reach a better understanding of the pathogenesis⁸ of the disease (Narayan 1997: 174).

Biological Basis: Evolutionary models of Type 2 Diabetes mellitus

Over forty years ago, geneticist James Neel (1962) formulated the first and still predominant evolutionary explanation for diabetes: ‘the thrifty gene hypothesis’. Neel’s (1962) original ‘thrifty gene hypothesis’ postulated that the ancestors of contemporary Native people became genetically adapted to patterns of alternating periods of feast and famine in that heterozygotes⁹ for the diabetes gene enabled the bodies to store the excess glucose as fat, which greatly increased their chances of survival during the time of famine. He held that diabetes mellitus functioned as a balanced polymorphism¹⁰. Because of the recent shift to a much more westernized lifestyle, which involves less energy expenditure and constant availability of non-traditional food, the set of genes developed to enhance fat storage in the body now work against Native people. When individuals

⁸ Pathogenesis: the origin and development of a disease

⁹ Heterozygote: An organism that has different alleles at a particular gene locus on homologous chromosomes

¹⁰ Balanced Polymorphism: When natural selection favours heterozygotes over both homozygotes, the result is balanced polymorphism.

with a 'thrifty genotype' are exposed to a continuous supply of energy-rich foods coupled with a reduction in physical activity, the results too often are obesity, low-glucose tolerance and Type 2 Diabetes.

To date other evolutionary models (such as 'The new world syndrome', 'Adaptation to a low carbohydrate cold environment', 'Northern hunting adaptation') have been suggested to explain the prevalence of diabetes in Native American populations. All these models proposed by Weiss *et al* 1984; Szathmary 1993; Ritenbaugh and Goodby 1989; cited in Szathmary 1994: 464-476 explain that the genes predisposing North American Aborigines to Type 2 Diabetes today were selectively advantageous in their pre-modern environments.

Environmental Basis: Diet, Physical activity, obesity and stress

A number of potentially modifiable factors, including diet, obesity, physical activity and psychosocial stress create the environment which is responsible for the emergence of NIDDM in genetically predisposed individuals (Narayan 1997: 173).

Diet:

Dietary factors had been linked with the development of diabetes over 2,300 years ago (Gulabkunverba 1949, cited in Narayan 1997: 176), but this had not been demonstrated consistently. Evidence suggests that a high-fat diet may be related to the development of the disease (Marshall *et al* 1994). Information for North American Native Peoples' linking dietary factors with the development of Type 2 Diabetes are very few, except for one study of the Pima Indians that found a possible association with a high-calorie diet (Bennet *et al* 1984). The traditional Pima diet was high in fiber and low in fat

(Knowler *et al* 1990), but this diet appears to have changed over time and is now more or less similar to the diet in the rest of the USA (Smith *et al* 1996). Similar changes in diet of other North American Aboriginal populations have occurred. Kuhnlein (1995) suggested that traditional diets consumed by Canadian Aboriginal peoples derived from local, natural environments are declining in use.

Calories and nutrients in the diets of many Aboriginal peoples started to come from a combination of traditional foods and market foods when the first trading post was established by European settlers that introduced items such as sugar, white flour and processed meat. At present, the majority of the Aboriginal population in Canada consume diets derived from market food, which is high in fat and refined carbohydrates (Kuhnlein 1995). Cleave and Campbell (1966: 19) theorized that over consumption of concentrated starch, sugar and refined carbohydrates places stress on the pancreas. Cleave (1975) contends that long-time exposure to an over loaded state created by high refined carbohydrate content would result in a gradual onset of Type 2 Diabetes Mellitus. Dietary changes include shifts in the proportions of macronutrients consumed (e.g. percent protein, fat and carbohydrate), deficiency of specific nutrients (e.g. chromium or zinc), and increase in specific food items (e.g. refined sugar) and total caloric consumption (Szathmary 1994: 471).

In Sandy Lake, Ontario, diabetes was found to be associated with the consumption of “junk foods” and “fatty” method of food preparation (Gittelsohn *et al* 1998). Dietary acculturation, particularly the substitution of modern food for traditional food items has been observed in many Aboriginal communities (Young 1994, Szathmary *et al* 1987). According to *APS I*, in Canada only 15% of the total Aboriginal population

still obtains most of their meat and fish from hunting and fishing (Statistics Canada 1993a). All these studies suggest that the role played by dietary changes in the onset of NIDDM in Native Americans still demands serious investigation (Szathmary 1994: 472).

Obesity:

Obesity is a powerful and well-established risk factor for the development of NIDDM (Knowler *et al.* 1981). The degree to which obesity is a risk factor for diabetes depends greatly on the location of the excess weight. Central or upper-body obesity is a stronger risk factor for type 2 Diabetes Mellitus than excess weight carried below the waist. Abdominal obesity among people belong to Salishan¹¹ language family, was found to be associated with hyperinsulinemia¹² in younger people and with elevated glycated hemoglobin¹³ concentration in older people (Daniel *et al* 1999: 458). Waist-to-hip ratio, a measure of central obesity, was more strongly associated with diabetes than body mass index (BMI), a measure of overall obesity. In contrast to these findings, Knowler *et al* (1983) findings among Pima Indians showed that increase in the BMI was also very significantly associated with an increase in the prevalence number of Type 2 Diabetes. Earlier age of onset of diabetes was also associated with the degree of overall obesity.

The association of diabetes mellitus incidence with obesity can be measured by using BMI (body mass index = weight in kilograms/height in meters squared). Muir (1991: 37) summarized the findings of an obesity study conducted by Young and

¹¹ Salishan languages are a group of languages of Western Canada. Some examples are Nootka, Nooksack, Squamish, Interior Salish and Thompson River Salish.

¹² Hyperinsulinemia is an endocrine disorder characterized by a failure of our Blood Sugar Control System (BSCS) to work properly.

¹³ Glycated hemoglobin: When someone's diabetes is not controlled meaning that blood glucose is too high, sugar builds up in blood and combines with hemoglobin, becoming "glycated."

Sevenhuysen using a sample of remote Cree-Ojibway communities in northwestern Ontario and northeastern Manitoba. Researchers in this study found that a larger proportion of individuals in all age-sex groups were “obese” ($\text{BMI} \geq 26$) including almost 90% of the women between the ages of 45 and 54 years.

Physical Activity:

There is no doubt that physical activity among Aboriginal people decreased in the transition from their “traditional” to “modern” life-styles. The *APS I* (Statistics Canada 1993a) showed that only 54% of Aboriginal adults in Canada participated in leisure time activities. Since excessive insulin accompanies obesity even among non-diabetics, and obesity generally precedes the onset of Type 2 Diabetes, obesity is thought to be diabetogenic¹⁴ (Bernett 1982). But obesity alone cannot explain Type 2 Diabetes. There is evidence that increased physical activity may act as a protective mechanism against the development of Type 2 Diabetes (Schranz *et al* 1991; Manson *et al* 1992), which is consistent with the observation that diabetes was apparently rare among North American Aboriginals in the past when they were a physically active agricultural and hunter-gatherer societies.

¹⁴ Diabetogenic: Causing diabetes

Stress:

Berry (1990) explained the issue of 'acculturation stress behaviours' among Canadian Aboriginal people, which includes lowered mental health status, feelings of marginality and alienation, and identity confusion and at the behavioral level, homicide, suicide, substance abuse, and family violence. The Aboriginal people of Canada have been under conditions of extreme stress for several generations due to the significant cultural, social, economic and political impacts of colonization and continuing deprivation. Berry mentioned that due to a lack of political power, Aboriginal people had to undergo some sort of adjustment or withdrawal. For Canadian Aboriginal people, forced withdrawal was in fact the action utilized by the government in attempting to first relocate and later assimilate (reserve and residential schools).

It was shown that the specific biological entity closely associated with stress brings effect on human physiology. The effect of stress on the physiological mechanisms involved in the development of diseases may be the best theory to unify evidence for a link between stress and disease. Epinephrine secreted in response to stress is known to increase blood sugar levels (Curtis *et al.* 1960; Treuting 1972). Stress and emotional problems can evoke a change in nutritional habits, leading to over-consumption. Treuting (1972: 96) hypothesized that long periods of stress resulting in long-term overeating and obesity might precipitate the onset of diabetes. Symptoms of chronic stress are generally defined as feelings of fatigue, lack of energy, irritability, demoralization, and hostility. It has been linked to the development of insulin resistance, hyperglycemia and hypertension, all risk factors for the Type 2 Diabetes. Whereas Szathmary (1987) says, as most of the studies (on stress as a diabetes risk factor) have

been conducted on patients with Type 1 diabetes rather than type 2, extrapolation of conclusions from one form of diabetes to another is problematic. Formal studies of NIDDM and stress in humans are rare. Research has found that psychosocial stress does influence blood glucose levels (Surwit and Feinglos 1988; Goetsch 1994), and it may be a factor in the advent of NIDDM in Western Samoa (Zimmet *et al* 1990). Glycemic control in diabetes is affected by stress under some conditions (Carter *et al* 1985).

Therefore, Type 2 diabetes mellitus may be linked to the following acculturation trends: dietary change that introduced refined sugar into the diet and increased the refined carbohydrate content combined with decreased energy expenditure (causing obesity) created by the adoption of sedentary lifestyles and westernization. Increased emotional and traumatic stress levels perpetuated by acculturation stress may also play a part.

Type 2 Diabetes: Aboriginal Explanations and perceptions

There is a paucity of research investigating perceptions of diabetes, causes of this disease and the coping mechanisms relevant to First Nations people (Garro and Lang 1993). Garro (1995: 40-44) carried out fieldwork with First Nations people in Manitoba to understand the causes to which they attributed their own diabetes and the increasing prevalence within their community. On the one hand, her research participants talked about diabetes as a disease that comes from being overweight from the over-eating of certain types of food and lifestyle habits. On the other hand, people referred to Type 2 Diabetes as a “white man’s” disease. Garro’s interviewees interpret this as evidence of continued disruption and destruction of their traditional way of life that began with colonization.

Lang's (1989) and Garro and Lang's (1993: 312-321) work among diabetic Dakotas in a North Dakota community reported similar perspectives of diabetes. She found that these participants also attributed diabetes to more than one factor: white man's destruction of traditional society and culture, and self-blaming because of a lifestyle that is out of balance and not congruent with traditional Dakota ways. They also raised the possibility that diabetes is not treatable with traditional medicine because it is a new disease. Very similar observations were found by Hagey (1984: 267-270) in one of the earliest studies investigating native explanations of diabetes in an urban setting. She described the explanations of urban clients attending the Native Diabetes Program in metropolitan Toronto. Urban clients also had similar explanation for diabetes, i. e. resulting from the White man's food, poverty, family breakdown and also from alcoholism. An additional finding was that these research participants viewed diabetes as a disease resulting from lack of spiritual strength. These studies view diabetes as having originated from lifestyle factors at the primary level, but at the broader level identify factors as being ultimately responsible for the emergence of diabetes--continued efforts of assimilation and eradication, and disconnection from the culture and tradition by dominant society. In my view, there have been little studies that have investigated the experiences of living with or coping with diabetes within the urban First Nations women's cultural context. This should be a research priority.

A Conceptual Framework for Understanding Diabetes Experience:

After conducting an extensive literature review on Type 2 Diabetes in the context of North American Aboriginals Peoples, I was prepared to build up a conceptual

framework in an effort to understand diabetes among urban First Nations women of eastern Ontario. This conceptual framework is enriched with the diverse theoretical perspectives which are discussed in previous section. This framework explores cultural, historical and medical interpretations, and experiences of chronic diseases as a critical or disruptive event of person's life as a significant factor. These concepts also help to understand the major social, cultural and historical processes that put First Nations people at risk of becoming chronically ill, as well as understanding coping mechanisms and disease management. It is critical to understand in terms of chronic diseases such as diabetes how people become engaged in the lifestyles that are dangerous to their health, what motivates them to seek medical care, or the other ways they are coping with the disease and managing life situations.

This anthropological approach to understanding the antecedents and consequences of diabetes among First Nations people is in concordance with the Aboriginal philosophy of health and sickness described by the medicine wheel. The Medicine wheel (See for example Warry 1998: 88) symbolizes balance in emotional, spiritual, mental and physical well-being. If one quadrant is thrown off balance (e.g. by diabetes), then the whole wheel is out of balance. This concept of the medicine wheel not only encompasses a holistic view of health and well being, but also recognizes the articulation of the individual with the community through socio-cultural, economic and political well being, and all of these with the greater environment in order to achieve normalcy in life. This concept may be expanded to explore the renegotiation of self in the face of diabetes and again at a community level the renegotiation with numerous elements of contemporary Aboriginal

life (socio-cultural, economic and political). Thus a healthy management of the disease can be achieved.

This conceptual framework serves as a point of reference that helps in analyzing and interpreting the information gathered. With the help of this conceptual framework, this thesis aims to offer an understanding of the perceptions of diabetes and the consequences of social, cultural, historical processes that are responsible for the emergence of this disease as well as coping mechanisms and disease management among the First Nations women of eastern Ontario in urban settings.

Chapter 4

Type 2 Diabetes: Its Causes and Consequences among Urban First Nations people

The discussion of Type 2 Diabetes among Canadian Aboriginal peoples in the contemporary context has little or no meaning without discussing the social, cultural and historical processes that have been involved in the emergence of this disease. It is clear from the discussion in the previous chapter that health and sickness among Aboriginal people are shaped to a great extent by the socio-cultural, political and historical circumstances in which they live. It is also clear that this type of disease incidence was more or less common in every corner of Canada. My research was conducted in Small Town, Ontario among urban First Nations people. According to their information these group of Aboriginal people migrated to this urban setting from different parts of Canada; few were also born and raised in this locality. While talking to them, one of the most interesting things I found was that there were a number of themes (e.g. childhood disease experience; significant social, political and historical changes) on which comments were remarkably similar regardless of age groups and peoples' original place of birth and residence. I did find different understandings of lifestyle and issues of management among educated professional urban Aboriginal people than among the people who have limited resources for their everyday living. In this regard, I also found dissimilarities in opinions among the people from different age groups.

The conversations I had during the interviews are presented here using direct quotes from interviews. My objectives for the interviews were to present the changing prevalence of Type 2 Diabetes in the context of peoples' memories of culture, society and

history. At the same time, it is also true that they did not share a single common understanding or experience of any of these or their relation to diabetes. There were many interpretations at the urban Aboriginal people and health care professional levels that were produced not only by peoples' common understandings, but also by their individual life experiences of diabetes as a disease, their perceptions of its causes and consequences.

These life experiences were examined together with medical, sociological, anthropological and historical literature on the life of Aboriginal people with special reference to urban Aboriginal people. In order to get a comprehensive picture of the subject under investigation, I also consulted several national surveys and government documents published by Statistics Canada, Health Canada, NAHO, the Department of Indian Affairs and Northern Development, and other government departments, as well as many other Internet sources. Critical understanding of these background literatures has helped me to understand the significance of the colonial experience in shaping the contemporary health issues among Aboriginal peoples (O'Neil 1986: 250, Frideres 1993: 257-280, CMA 1994: 21, RCAP 1996: 111-361, Milloy 1999: 77-107).

Emergence of Diabetes: Impact of Social, Cultural and Historical processes

As I mentioned earlier, the people who participated in this research have moved to this urban setting from different parts of the country. They tend to remember a healthy childhood, no matter what their current ages are; there are significant differences in the types of sicknesses that people recall from their early years. Early memories of sicknesses among the participants' over age forty include tuberculosis, chicken pox,

arthritis and pneumonia. Following are the conversations I had with several people over age forty.

...tuberculosis and pneumonia those are the two most prominent...I remember. I have not heard about diabetes.

...I had tuberculosis. One of my lungs was taken out...all of my brothers had tuberculosis. I have never heard about diabetes when I was young.

...Not much, I remember chicken pox...I remember because I had it when I was a child. I remember people being sent away to hospitals because of that tuberculosis...other than that I do not really remember much health issues.

Participants being born and raised in different parts of Canada share similar sorts of memories about disease incidence that they have encountered in their home communities. This kind of disease trend was also recorded by other authors such as Milloy (1999: 77-107) and Kelm (1998: 3-18). Among all the diseases, tuberculosis certainly occupies a prominent place among the memories of the over-forty age group. Early memories of this cohort also include arthritis, STDs, alcoholism and drug abuse. Janet, aged seventy-four at the time of my interview, said that her mother and some of her aunts had arthritis. Ada, in her mid forties, remembers the growing concern of STDs in their home community and she says “in our schools we got awareness for sexual behaviour.”

In contrast to the older cohort of research participants, people in their thirties and twenties who are living in this urban setting for a longer period of time either being born and raised here or having migrated here at an earlier age primarily referred to alcoholism, drug abuse, obesity, cancer, heart disease, malnourishment due to poverty, mental illnesses and obviously sugar diabetes. Following are the conversations I had with different younger people that reflect their memories of childhood disease incidence.

...alcoholism and obesity I think those two were the biggest concern and ...also high blood pressure related to obesity in reserve. In cities...heart disease was the major concern during my growing ages.

...Oh...okay...now if I look back I see alcoholism and drug problems were the major health concerns.

Olga, in her twenties, recalls that when she was very young diabetes was not that prevalent, but now it is more of a concern. Mary-Ellen, who is now twenty-four said that now diabetes is a pretty serious and growing concern and she also mentioned that in the urban setting a lot of people have diabetes. She continued by saying that older people are suffering from diabetes, but that her friend who is only in his early twenties has also been diagnosed with diabetes. This observation is very similar to the results of scientific investigative results provided by other researchers (Health Canada 2002: Diabetes Fact Sheet, Young *et al* 2000: 563). These narratives suggest that diabetes is certainly perceived as a recently emerging disease whether the narrator is now young or old, or does or does not have diabetes. These narratives also suggest the changing epidemiological profile of Aboriginal people, which is again consistent with the published literature on diabetes among North American Aboriginal People reviewed in Chapter 3.

Diabetes as an emerging disease: Causes and Concerns

During the course of interviews, I found that Aboriginal people regardless of their age and gender identified “food” as a core factor, which is responsible for the emergence of diabetes among them. They also talked about physical activity and stress. The diet of many Aboriginal people has undergone rapid change, from a fibre-rich, high protein, low saturated fat ‘traditional’ diet, to one in which refined carbohydrates and saturated fats

predominate (Kuhnlein 1995). Historically, alteration in traditional diet started with the arrival of Europeans and subsequent associated environmental changes (Kelm 1998: 25). During my interaction with Aboriginal People, they primarily blamed European-introduced food and they think that had an impact on the manifestations of their present day health status, such as diabetes.

...I think the introduction of European food certainly plays a role... you know we as Aboriginal people never drank cow milk...only the breast milk. Yes, we never farmed animals...after breast milk there was no milk. Our children were breast fed longer, after that our sources of calcium came from greens. So we had lactose intolerance...I think the five white elements—the sugar, salt, flour, lard and milk have to be explored...you know government dropped flour, lard, sugar as staples in reserves. Those things were staples in their eyes, but those were not staples for us... I believe long term intake of those things generationally has now impact on diabetes prevalence.

...basically what happened, the visitors came and genocide became part of their culture towards us. In order to accomplish this they killed buffalo, which was a major source of our clothing, tools, medicines and food...so having take those things away and taking other things away that we were hunting ... all these had changed our diets. We could no longer eat the foods that were traditional to us, we could no longer harvest and hunt...eventually we started to eat the type of food that was brought to us by other cultures. Lots of treaties were signed and we were supposed to be given X pounds of this and that...but we were ended up being given totally substandard food, that goes on to this date today...so we end up eating bad things...so once we were changed, our diseases got far more whitish. Food is a catalyst to everything.

Food. Period. It is all about food. We are more affected by diabetes because our diet, our whole receptors have changed, our taste have changed...we no longer have access to traditional food. Why are we more susceptible? Because of genocide factors... If you look at residential schools, the government charged the keepers of residential schools to feed the children terrible foods as an experiment. So it is no wonder that we have ended up being diabetic, high blood pressure.

As we all know, changes in Aboriginal culture were not only in diet and were not that easy and straight-forward. A great series of alterations have afflicted aboriginal

lives—relocation of settlements; loss of language, cultural identity, tradition and pride among Aboriginal people; poverty and cultural genocide. Even today Aboriginal people are facing similar life stressors. All these factors have an ever-encompassing impact on their lifestyle pattern of which dietary changes are only a part.

Changes in Aboriginal lifestyle: Past

From the childhood memories of interviewees over age forty it is evident that land food occupied a significant portion of their diet. They discussed primary reliance on land resources, such as moose meat, deer meat, fish and goose meat. These land foods were supplemented by dry food from local stores. Louise, now forty-six years old, said “...I think there was balance in diet...you know...typical cheese, butter and milk from the store, but we still always had fish and meat...moose meat and deer meat and sometimes there was not. Then soups and bannock, I mean soup was a big thing...soup was there for everybody.” But some people in the older age bracket (presently in their sixties and seventies) remember relying on bush foods for their subsistence.

People remember their childhood subsistence pattern. Some had parents employed on a seasonal basis, although some were self-employed. This was consistent with the findings of other authors (Honigman 1948, Kelm 1998). Jane, now in her forties remembered “...my father was a hunter and a trapper...when he started to have family he had to settle down...and the fur trade was pretty much died away and he had to take seasonal work ... like for example the fishing lodge...during the summer time mostly Americans came up from South and he will go fishing, guiding...you know... my mother too the same way”.

Gradually store bought food started to appear in higher proportion in their diet because of the change in subsistence patterns and the availability of resources. Due to the high cost of transportation and the lack of refrigeration facilities, imported foods were of low quality and expensive. Jane said, "...because years ago our people relied primarily on...you know on food of the land. So there was not any sugar or anything like that in diet and you know when people had to adapt and lived in communities and eat from the store...so there were new things that were introduced into their diet that they were not used to." Louise recalled that they were living off the land partially, it was half and half grocery store. People also talked about their residential school dietary experience which indicates consumption of higher concentration of carbohydrate (macaroni, potato, porridge etc). This is also indicative of higher incidences of diabetes among Aboriginal people.

...I was in residential school for a few years and we were not fed very well. They did not give any nutritious food. Milk had nothing in it. Macaroni and cheese or potato and other vegetables that we grew in the garden. ...because half a day we worked in the garden ... certainly we had meat but not all the times...you know lot of breads and things like that.

...like if you look into the residential school system, what did children eat there? ... I mean my grandmother went to the residential school...there she was raised on "mush, means porridge, for her growing ages...when she was developing, carbohydrate and fat and probably some salt for flavour...you know. I heard stories that kids worked in farms, they picked apples and pears and they never ate one, they were not allowed to eat one...you know impact of that on their mental and physical health was probably huge.

Jane, now in her forties, gave a slightly different description of residential school diets. She said her residential school experience was quite different than her mother's "...especially in terms of time you know...when my mother went it was 1940s and they

did not have very much in terms of diet compared to when I went later...It was not that bad...I guess...they fed us three meals a day...but yeah...I guess...you know just the things that our people were not exposed to for example canned fruits, there was lots of sugar in canned fruits and of course additives in foods, preservatives...things that our people never had.”

Julie, (fifty-two years old at the time of my interview) shared her childhood stories with me. She too thought that diet was an important role in the growth phases of human beings. She gave a first hand experience being raised on Children’s Aid “...you know they just put us out to work. They didn’t feed us very well. For breakfast we were allowed toast...we were hungry throughout the day. You had a piece of bread with mustard on it...lunch consisted of mustard sandwiches, no meat or no vegetables...that was usually done by supper time.”

From the above discussion, it is evident that market food started to take a major share in Aboriginal diets, although interviews suggest that their significance to individual diets was variable. Changes in diet were accompanied by changes in activity patterns, as people no longer had to work hard physically in exchange for subsistence. Permanent settlements along with new technologies and innovations have led Aboriginal people to live a sedentary life. A health care provider says, “...but the whole system of imposing reservation that supposed to be a nomadic lifestyle to a sedentary, artificial system has to have an impact as well, I believe so...hunting, trapping and fishing by and large that have been eroded.” In the epidemiological literature, the emergence of diabetes is broadly linked to concomitant changes in lifestyle with special reference to diet and physical activity (Szathmary 1994: 470-475; Joe and Young 1993: 13; Narayan 1997: 176-177).

Discussions with people who grew up in different places of this country also indicate that the story is much similar for them. While there is an association between diabetes and lifestyle change, there have been many other subsequent changes in the lives of Aboriginal people as suggested by literature (Preston 2000). Schools, hospitals, welfare and permanent settlements in reserves with access to health, education and social services had transformed this nomadic people into a sedentary community (Preston 2000). Added to these are the legacies of the residential school that disconnected generations of people from each other, their traditions, their language, and their pride and dignity (Abonyi 2001: 96-100). Along with the changes in diet and physical activity patterns, the series of alternations that residential schools produced have intergenerationally affected Aboriginal life. These changes undoubtedly play a role in the contemporary context of diabetes.

Residential Schools:

Residential school experiences feature significantly in the childhood memories of people now in their thirties and older. Despite the forced relocation to schools by the RCMP, various other reasons had led parents to send their children to residential schools. One woman said that her mother had a really bad case of arthritis and it was difficult for her to look after her kids, therefore they were sent off to residential school. Jane, now in her forties remembers, "...you know during my mother's time for example, when they were forced to go...but sometimes they had no choice to go...I think my mother and her younger brothers and sisters went because their father had died and their mother had got tuberculosis and she had to go to the hospital and there was no one to take care of

them...So they were all sent off to residential school.” For her own case, Jane told me that she went to the residential school because she wanted to be educated further and there were no high schools close by. Although in her case it was not a forceful relocation to the residential school, she still remembers those days as a very different experience, “...being sent to the residential school was a tremendous change...just the fact you know ...you are placed in a foreign environment...you know...the big residence with bunch of other kids...hearing English all the time...cannot speak your own language...lots of changes.”

Some residential school survivors and front-line health-care providers talked about changes in lifestyle patterns that were brought about by residential schools, while others talked about loss of pride and dignity in their own culture and language. The following conversations with residential school survivors as well as with other community members and health care professionals are recorded in my audio tapes.

...Most likely residential schools have changed our lifestyle...there I was introduced to the things that our people never had...yes, I was exposed to sugar and candy but not that much...well we were given desserts and other sugary foods in residential Schools...but that changed my eating habits.

Residential schools have changed their lifestyle a lot...It institutionalized them. Lots of things that they learned there, it was carried to their children and then to their children's children and it made them sick.

...no doubt that there is the ramification of what comes out of the legacy of residential schools...if you are in tune with yourselves in your formative years as a positive image...then that is good for your holistic development...but if that is directly attacked then you are going to go up thinking...you know...you are going to be less in tune with that embodied sort of sense of being entitled to be active...to speak and do enjoy your body in a good healthy way.

The residential schooling system was a very focused effort to rob

Aboriginal people of their culture and language and traditional practices. We now see the multigenerational effects of that...with the loss of identity and language they have no place in this world and they don't talk with pride and dignity anywhere...so they struggle with low self esteem...with the loss of culture they have lost the traditional ways of activities and foods of course...hunting, trapping, farming all abandoned...so they were transformed to a sedentary group of people struggling with unemployment...sit in front of the television...smoke, drink and eat nontraditional food.

...relocation to residential school... in an environment which was very alien...not only alien...there was a lack of love...lack of expression of love...there was regimentation...loss of family...loss of language...loss of community...loss of culture which ends up over time may be combined with the other factors...ah...to a kind of historic trauma that really does impact upon people...their health and diseases, especially mental...mental disease and also physical disease because we all know that mind is very much related to health and if one is carrying that burden with one and had the unhealthy lifestyle...together with whole lot of other factors make it very very difficult for Aboriginal people in terms of mental and physical health.

Some other people talked about the 'negative structuring of life-style' that they feel had been imposed by residential school system. They also mentioned the loss of parenting skills.

The following conversations express the experiences of people that have stayed at residential schools, and cast a shadow that extends to the generations that followed.

...in residential schools what they have gone through is the negatively structured life-style that they have brought to their family life...for kids, there was no flexibility...little or no communication between mother and child...they had to either follow strict rules set in by their parents or severe punishment.

...lot of kids were there (residential schools) for ten months and they went home for two months...you know and their parents did not have much to say...and that time priest was the God almighty and his words were gospel...parents had to listen to them, that was very sad...parenting skills changed.

One person said that residential schools were a deliberate or overt effort to stunt the spiritual, cultural, physical and emotional growth of the Aboriginal communities. But people are trying to get out of that vicious cycle. As a knowledgeable Aboriginal person said, “you are getting to learn to know who you are to carry out pride and dignity in yourself...education is a very important tool...so that we may be able to pass on awareness to the future generations towards a healthier and positive lifestyle.”

Historically, the introduction of White man’s food or market food, the reduction in physical activity and the legacy of residential schools are some of the factors people discuss with reference to changes in lifestyle. It is true that residential schooling system is one part of displacement of all the structurally violent relations that Aboriginal people had with the dominant power. But there are other factors of changes those are often considered as improvements in the quality of life, which have also contributed to bring new challenges, such as Type 2 Diabetes.

Changes in Aboriginal life-style: The Present

In an attempt to present an understanding of Type 2 Diabetes among urban Aboriginal people, it is necessary to examine some important determinants of health in the present day urban context. In this regard, interviews with diabetes patients, community members and health care professionals provided a greater depth of understanding about the contemporary factors that influence the life-style patterns, including dietary choices, physical activities and stress. Exploration of present health determinants in this urban setting will help us to understand why the prevalence of diabetes is on the rise.

As we have mentioned earlier in 2001, almost one-half (49%) of the population who identified themselves as Aboriginal lived in urban areas¹⁵. In another study of migration patterns based on the *Aboriginal Peoples Survey I*, it was shown that in cities in eastern and central Canada more than 30% of in-migrant families were lone-parent families with limited resources (Clatworthy 1995: 247-254). On the one hand there is a growing kind of middle class professionals who are working in organizations and living in cities and raising their children in families that are not very unlike those of urban mainstream middle class families, but at the same time there is a real substantial number of urban Aboriginal people who are on the street, who are very poor and who have no access to other lifestyles. The literature indicates that there are also large numbers of Aboriginal homeless or street people in large eastern cities of Canada, although these populations have not been studied as intensively as those in the western cities (Royal Commission on Aboriginal Peoples 1993: 82; Native Women's Association of Canada 1995: 13). In this study, I did not have direct access to interact with Aboriginal street people in this urban setting, but I gathered some real glimpses of their struggle and existence from front-line health care providers. I had interaction mostly with people who are educated, energetic professional Aboriginal people, and on the other hand with people who are surviving on some sort of limited resources and access to services due to various reasons (old age, low income, reliance on old age pension etc).

In the course of my interactions with urban Aboriginal people, they primarily talked about poverty, food insecurity, unemployment and stress in terms of life-style choices and their consequences. In the course of discussion with health care providers

¹⁵ Statistics Canada Website:
<http://www12.statcan.ca/english/census01/products/analytic/companion/abor/canada.cfm#6>

and front line workers, the issue of food insecurity was raised again and again with a great emphasis. Food insecurity was a major theme that emerged from the OFIFC (Ontario Federation of Indian Friendship Centres: 3) October, 2000 report. The prevalence of food insecurity among Aboriginal people had also previously been established in a paper (McIntyre *et al* 1998: 7-9, 15) published by Applied Research Branch, Human Resources Development Canada (HRDC). This paper had found that Aboriginal families were four times more likely to report having experienced hunger than did households representing other groups. The OFIFC child poverty study confirmed that food insecurity and hunger are pressing issues for urban Aboriginal people as well (OFIFC 2003: 1). People made the following comments regarding food insecurity, poverty and unemployment during the formal conversation I had with them.

...so food insecurity, not having access to healthy food and I am also saying poverty...I mean when your income is challenged, how do you access foods in five and ten dollar pieces...five bucks meal deal from McDonald's supposed to be the best bet...I mean after rents you simply don't have enough to do whole months or couple of weeks grocery shopping when you are on assistance.

...specially unemployment in an urban setting...Unemployed people live in social assistance...they tend to be very present oriented. When one is only living on social assistance and when you get the cheque and you take care of today...then there is definitely a present orientation...there is hardly a future planning. Often for social assistance people, money just gone within a first few days of the week and they are right on the edge of the struggle until the next cheque comes.

...well, definitely we see that for Aboriginals as well—obesity and food habits. Very related thing to me with poverty and food habits and patterns that people have adopted because of poverty and not having access... not only lack of a great deal of understanding and information about food, but access to food that is healthy.

...so I think you know for sure there is some possibilities of genetic link to diabetes...I mean if you think any ethnic group of people and change their diet radically and take away their economic livelihood and put them in impoverished conditions then I think we see this diabetes.

In this urban setting people also identified social isolation and lack of awareness works as determining factors in information sharing, which also regulates lifestyle choices. Aboriginal communities in urban settings are living as marginalized communities. As the Royal Commission on Aboriginal Peoples (1993: 90-92) has observed, Aboriginal People have been and continue to be on the bottom rung of the economic ladder in Canada and they have higher rates of unemployment, earn less, depend more on welfare, and suffer from extreme poverty more than non-Aboriginal Canadians. It was also mentioned that lone-parent families, large families and women are hardest hit by adverse economic conditions. Compared to reserves, the urban lifestyle is not so tight knit in cities and they do not live in urban areas as a community. Everybody is so spread out that they do not know who their next-door neighbor is. Olga, in her twenties now and has very close contact to her reserve and says, "On reserve, I see a sensitivity toward others but in city I don't. In reserves we do so much like together...people are much isolated here...you have to be on your own." Social isolation sometimes becomes a barrier to knowledge sharing that brings awareness about anything from diet, exercise, health, education and so on. Sometimes people from lower economic levels are socially isolated because they do not have the resources to take part in community activities. For example, in cities Friendship Centre play an important role in order to creating opportunities for social interaction among Aboriginal people.

However, many people I talked to said that they cannot always participate or join

programs because they have to take public transport or depend on commuting systems provided by Friendship Centre. Public transport costs money. Some people live so far from the friendship centre, and therefore they don't think of going there. Some of them simply do not have information about what is going on in and around the city. This create a web of factors that put these groups of people at the margin of information flow, which is again very important for their health and well being. One front line health worker told me,

“ I would say that awareness plays a big role. I do not want to minimize anybody's capacities, but I also know that income challenges tend to lead you on the margins of the information flows. You are not accessing the Internet; you are not buying the Globe and Mail everyday. So you are not going to see all the articles that are out in the public spheres...I mean what is good for your health or what is bad...After you get your kids from the day care and after you visit your social worker and so many else you have to do...you just...you know...going to the community center to get on to diabetes information, I think will be the last thing on your mind”.

People also mentioned that in cities life is much faster than reserves. They talked about how the fast pace of everyday life influences people's dietary choices.

...but also there are other factors that play role in terms of selecting diet. Like in an urban setting time is the most important thing...like when I was a student that was easier on campus to have a big burger instead of going home and cooking from scratch, so time is a big issue here.

...Reserve life was little more laid back. Like here is always rush, rush and rush...I see my daughter's family...they work and they get to fix supper, and fast foods like KFC interfere in their diet...lot of fast food. They don't cook from the scratch at all. Convenience has changed our eating habit.

In light of the findings from the study (Health Canada 1998: 7) based on *APS I* (Statistics Canada 1993a) that revealed that First Nations women are more affected than

men by diabetes, I was curious to know peoples' understanding or their perception regarding this matter. The *APS II* (Statistics Canada 2004: 13-14) indicated higher incidences of diabetes among older Aboriginal women. Nearly one in four Aboriginal women aged sixty-five and over had been diagnosed with diabetes, compared with one in five Aboriginal men. The situation was the opposite in the total population. About 15% of senior men aged sixty-five and over had been diagnosed with diabetes, as opposed to 11% of senior women. The following are the opinions I gathered during my interaction with community members, health care providers and front line workers. More or less everybody put importance on less physical activity and limited dietary choices in relation to their role as a mother and care giver; and said that these may have some impact on excessive weight gain and, in turn, increased prevalence of diabetes among Aboriginal women. These understandings are again consistent with other authors' (Eaton 1977, McIntyre 1986, Ship and Norton 2000, Martin and Bell 1991, Evers 1991) findings discussed in Chapter 3.

...In my opinion, gender related roles facilitate more activities for men and less activity for women and makes women more sedentary. It becomes more problematic because women by and large are caregivers so when you have five years old, seven years old and eight years old...you are less free to be active. I think gender plays a conditioning role in terms of what cultures and individuals expect in terms of opportunities. I think men have more opportunities to become NHL hockey players, to play hockey and lacrosse...whereas women do not have those opportunities.

Women are much of a beauty like mother earth is. But not only to give life but they have the body texture to contain (spiritual means), women can take more. When they give life...9 months...the amount of pain she tolerate...men do not understand the gift that bestowed on to her that she can easily consume much. She is eating for two through the developmental stages of lives. If they do not educate themselves properly through the consumption of what they do, they are going to restore it...that's the beauty of what creator made available for women. But if they have not been brought up to recognize the gifts then how can they educate children.

Generationally if she has not been brought up then she is going to restore all those negative shifts within herself. She has that capability of dealing with that but she also has that ability of restoring it.

I think women as a care giver always put themselves at last, when you are poverty stricken then you will feed your kids first and you take last...if we think about women in urban areas...women are the heart of the family, what they provide, what they cook, what they model that affects the children...the grandmothers, the aunts, the next generations and definitely a big issue is gestational diabetes, we know that if you have gestational diabetes then you and your child are at risk of developing diabetes later on and that could be why more Aboriginal women have diabetes than men.

I think, you know...they take care of the whole family and I think it is...just an added stress and diet. They are either working moms but again they are home moms too...they have to deal with everything around the house, kids and husbands. I think that is the diet, whatever is easiest and quickest to eat.

Some people do mention that women tend to face added stress in dealing with everyday life situations. Women as mothers, as care givers, as wives always carry extra burdens of work and jeopardize their personal health and wellbeing. Being overwhelmed with responsibilities of everyday life, the amount of stress they experience produce negative health outcomes. As we know, urban Aboriginal lone-parent families are mostly female lone-parent families, and so the tremendous amount of pain and sacrifice these single mothers share is easily understandable.

Well, stress in a sense that when people are under stress...their immune systems weaken...so it is easier for them to get disease. So stress just puts a great deal of pressure to one just not only physically but mentally...so if stress is not released in any sense like taking part in sports...I think it is activity, physical activity probably have role in it. Controlling ones stress and participating in exercise and controlling ones diet if it is possible and I suppose smoking and drinking is a part of that.

I think stress is an issue. I saw families with no alcohol abuse, but single moms with two to five kids, limited resources, lack of education, job insecurity, poverty...all these put them at risk of leading their normal lifestyle—to eat proper diet, pay rent, make sure that they don't get sick as

they have to take care of their children...all these factors make women stressed. I must say stress of parenting responsibility.

I exactly don't know why women are more affected...but I guess it is the frozen food and fast food...fast pace. Stress is everywhere...in your home...in your job...you are not doing only one job, you are doing ten jobs. It may not be in your job description. But that is what you do and your whole life is dependent on your pay cheques.

Perceptions of lifestyle choices among the professionals and community members were explored and it is clear that there is a very sharp difference in life style choices in terms of the socio-economic conditions (poverty, food insecurity, social isolation). It is also obvious that factors associated with lifestyle choices are embedded in issues such as expense and access to resources (cost and availability of healthy food, cost of recreational facilities, transportation problems, etc.), fast pace of urban life and stress. Front line health workers pointed out that there are differences in physical activity patterns and stress levels among men and women, which may in turn regulate their food choices. On the whole, the contemporary lifestyle of many Aboriginal people in this urban setting is characterized by fast food, sedentary activity patterns and particularly for professional Aboriginal peoples, a fast pace of life as well as added stress. The significance of the emergence of diabetes in relation to other health concerns, as well as perceptions of causes and concern for diabetes indicate that it is surrounded by a complex array of issues for these urban Aboriginal people. In Gaultung's (1980: 109-139) terms, the emergence of Type 2 Diabetes among urban Aboriginal people is one amongst various other outcome of very complex nature of structural violence. It is structurally violent, because of a lack of choice for food, physical activities and recreational activities; and stress had major, disruptive and negative effects among the Aboriginal people that could have a

massive impact on their health outcome. The following section makes an attempt to shed some light on those issues.

Perceptions of Diabetes:

An exploration of past and present determinants of lifestyle choices certainly suggests reasons for the current increasing prevalence of Aboriginal Type 2 Diabetes both at the bio-medical level as well as in Aboriginal peoples' understanding. The differential explanations on the emergence of diabetes in the previous section, however, indicate that urban Aboriginal people do not necessarily share a common understanding of the consequences of major social, cultural and historical processes in relation to diabetes. There are many interpretations of diabetes as a disease both at the lay and professional levels; these are produced by peoples' individual life experiences. In the context of the complexities of present day urban life, it is required to understand these varied perceptions of diabetes and their consequences.

Why Do We Get Diabetes?

There are many explanations given in the previous section for who has diabetes and who gets it. From medical professionals and front line health workers to community members and diabetes patients, the people interviewed for this project were clearly aware that a lack of appropriate lifestyle choices might be involved in relation to the increasing prevalence of diabetes among Aboriginal people. There is more to the story, particularly from the perspectives of the diabetes patients and non-diabetic community members. Some people believe that fast food and store bought foods may be implicated in diabetes,

not only because they are calorie dense, but that canned food contains lots of preservatives that have negative health effects. Olivia, now seventy-seven years old says, “in the bush we ate wild food, but in the city now we eat store-bought food...that is not good for our health.” Other people also made similar sorts of comments.

It is the kind of food you eat...we are now used to get fast food, prepared food. To me when I see it, it has lot to do with frozen foods like pizza pops, and the convenience of these fast foods...I see it as being blamed on fast foods and western foods...you see...westernization has a hand on it.

...I remember I was working three days a week, I also had a full time course load. Trying to work more than full time between work and school...so for me time was a major issue...I also think, if you want to have burger or fast food there is lot more access in cities than in rural setting. Also first time when people come to an urban setting they eat lots of processed food. If you go to supermarket, there are lots of processed foods with preservatives in it.

People also talked about other factors that may relate diabetes to such as the lack of physical activity, diet and obesity. In fact, the lack of physical activity, obesity and diet are most frequently mentioned altogether.

In my case I think it is the eating habit, the type of food, being over weight...when I was diagnosed, I was quite overweight. So it is important being able to move around and burn off extra weight.

...it might have been my weight. After I had diabetes I lost weight. So I think this; it is the kind of food I eat and lack of exercise also.

Similar perspectives on westernized foods have been reported in other Aboriginal communities (Gittlesohn *et al* 1996: 375-377). There also are people who believe that diabetes comes form White men’s food. This is not unlike the perception of people I interacted in Small Town, Ontario where they had blamed westernized food for the increasing prevalence of diabetes. Surprisingly enough in this urban setting, people are blaming western food for the diabetes incidence and at the same time they are also

blaming themselves for the kind of food they consume or the kind of lifestyle they pursue.

Another explanation of diabetes is that it develops in people because they are stressed.

In my case diet and stress were the two major triggering factors...when I look back at my life...then it was quite stressful. At the time we were building a new house, building by ourselves...I was pregnant at that time. I had just recently lost my mom...it was about a year at that time, I think I was just dealing with all these things at a time.

Food and stress too...my sugar gets all out of whack when I am upset. So I think there is a relationship between diabetes and stress.

There have been a number of studies in recent years that indicate that stress does play a role in glucose metabolism (Surwit *et al* 1988; Goetsch *et al* 1994). Szathmary (1987, 1994) explained that stress may play a large role in the onset of Type 2 Diabetes, particularly in peoples experiencing acculturation, as has been suggested for Western Samoans (Zimmet *et al* 1990). The notion of stress and its potential role in diabetes appearance is described under the subsection 'Etiology of diabetes' in Chapter 3.

In the course of my discussions with an Aboriginal traditional healer, I came to know about his opinion of stress and its relation to diabetes. According to him, when someone is stressed his/her immune system gets weakened and therefore it is easier to get disease. He continued by saying that if stress is not released in any sense (through physical activities, meditation etc) then stress creates a great deal of physical as well as mental pressure.

In order to understand 'why do we get diabetes' from the Aboriginal people's perspectives, these discussions focused on socio-economic conditions and its impact on urban Aboriginal people.

...it also could be the way I ate. Sometimes I crave sweets. When I have money, I go and buy some donuts. I can eat that whole box to get rid of craving, I can eat six donuts and five donuts... I still do it once in a while, because now I can't eat sweet...I crave for sweets, I go to have sweets when I have money...I do not care about diabetes...regardless...some day I feel happy next day I am back to my old self again...so I do what I want to do. I did not change anything.

The comments above are significant because in her case, she equates sweet consumption with poverty and depression and social isolation. Higher amounts of sugar consumption can cause obesity, which in turn may lead to diabetes. As Sylvia, in her seventies, says, "it is all from sugar...it is sugar diabetes. It comes from sweets". In relation to sweets, people also mention alcoholism, because of the higher concentration of sweets in alcoholic drinks. One person said that he did not realize before taking a course that one of the growing factors that affect diabetes is alcohol, and he also was not even aware of the high concentration of sugar in a bottle of beer. He also said that alcohol is an old factor that they have started to consume at an early age of their life. As Europeans introduced alcohol, it negatively affected generations of Aboriginal peoples' health, therefore, from the above perspectives, it might be safe to say that consuming too much sugar may cause diabetes.

Community members and patients differ from health care providers and front line workers, researcher and Aboriginal Elders in their perceptions of why Aboriginal people get diabetes. Discussions with the specialists focused beyond diet, access to resources, physical activity and psycho-social stress; and provided deeper-rooted explanations for why people put their lives at risk. They mainly pointed out that many problems are directly linked to cultural transitions, loss of language, lack of communication, loss of identity, pride and self-esteem among Aboriginal communities. Their comments also

indicate that the situation is much more complex in cities. A front line worker says, “...like teen-agers and their self-image...when you are in city and you are in high school, it is hard world out there. There is lots of bullying and as an Aboriginal teen-ager they have different body shape...they think they are bigger, it is very difficult that affects their self-esteem, motivation and how they treat themselves, how do you love yourself,...your self love,...lots of teen-agers do not have that, and they end up doing more harmful behaviours.”

First Reaction to Diabetes Diagnosis:

Health care professionals differ in their experience, from the patients and community members. The response to diabetes diagnosis and fears about developing diabetes vary a great deal. Hickey and Carter (1993: 462) explained that accepting a diagnosis of diabetes is difficult because it may be largely asymptomatic¹⁶; therefore people take less interest in dealing with its potential seriousness. Some health care professionals see this as a denial.

I think a lot of people already know.... when they are coming they already know, and then there is just a denial...people don't really believe that this is something you can actually live with, there is almost like a fatalism sometimes, to some extent.

The comment made above is also consistent with a medical professional's opinion, when she said that there is sometimes 'desensitization' to the seriousness of the disease. From her first hand experience she saw that many of Aboriginal people grew up in families in which everybody is diabetic and takes insulin a few times a day; then

¹⁶ Asymptomatic diabetes: when there are no signs and symptoms of diabetes complication is present and the diagnosis is an incidental finding.

diabetes is just normal. They then develop the notion that just the drug will help and they don't have to do anything else if they get on the needle. So, sometimes there is a denial of the diagnosis of disease; again on the other hand there is desensitization or fatalism towards the outcome. In regard to fatalism or hopelessness Hicky and Carter (1993: 458) explained that struggle for existence in a new environment (here urban environment) often lead to overindulgence of available self satisfying activities such as eating and alcohol use. The eating can lead to obesity, and the alcohol to less effective self care. They continued that further the issue of poverty could lead to despair and this despair again combined with a perceived inevitability of diabetes can result in hopelessness, which is again devastating for diabetes.

Additionally, another front line health care worker alluded that in her experience people usually seek medical attention when they feel seriously sick from the complications of diabetes. According to her, Aboriginal people have a higher level of tolerance for any discomfort. She has experienced that Aboriginal people usually come for medical attention when first time they face problem with vision: they complain about blurred vision or frequent urination. A similar perspective was also found when I was discussing with another health care professional, where she said that most of the time Aboriginal people come to know only when there is a crisis.

Persons with diabetes shared their stories of first diagnosis of diabetes with mixed response. For some people it was quite acceptable from the beginning, while for others initially it was a sort of shock and disbelief. For some the period of denial and then acceptance took as long as many years, while for others it was as short as only a couple of months. Julie, fifty-two years of age, is a diabetes patient who says her first reaction to

a diagnosis of diabetes was, “nothing; you know...okay...I have high cholesterol, hypertension and one more. So give me the pill...” A very similar kind of expression was given by another patient. He said when his diabetes was diagnosed there was actually very little reaction on his part when found that he had the disease; so he had started to learn and educate himself about the disease and its management. Another women, who is in her late thirties now, could not accept this diagnosis of disease right away. She said “...it was very upsetting; sort of why me? I have this, and that, and again why me? I have seen my father taking insulin, so I thought oh...no...I can’t handle that, that’s too much. I think in the beginning...having diabetes was a quite shock to me, and trying to manage it was kind of hard at first, and then I was trying to read articles...until a year passed. Then I was accepting it and coping with it, but it took a while.” John (twenty-seven) says that, for him “It was a little bit of disbelief and shock. It affected my life negatively...it was little hard initially and also unbelievable...at that time I was in university and I ended up dropping classes, just because I had trouble focusing on my studies, and I had to live in this city on my own...so it was hard to find someone to talk about, but my fiancé was very supportive...yeah, first few months it was hard...after that I got to accept that and realize that I have to deal with that.”

Some patients believe that it is just a matter of time before they too will be diagnosed with diabetes, because many of their family members already have diabetes. As Adna, now in her sixties, says: when she was first diagnosed with diabetes she was a little upset, but she knew that it was coming. As her older sister died from complications of diabetes, a year or two before Adna was diagnosed. A sister closest to her in age was also diabetic by that time.

I have found a very similar line of thought expressed by some non-diabetic community members. A lady in her late thirties says, “I know it is coming, because my mom has it, my all aunts had this...yes I am worried about this. But I am much more worried about its long term complications...I saw my step-dad...he had high blood sugar and all sorts of complications from diabetes.”

Many front line workers and health care professionals concur that people do worry about long-term consequences of diabetes, such as kidney failure, limb amputations, and blindness. Similar perspectives were also offered in conversation with research participants. Following comments people made regarding their perceptions or concerns about diabetes.

...to me diabetes is a long term health problem...if not managed properly, in long run either amputations or kidney or vision problems.

...diabetes—blindness, amputation and difficult life, especially as a senior...I am afraid I do not want to have that kind of difficulties.

Even for these people the tragic consequences of diabetes is so far in the future that it seems a distant concern in the face of more immediate issues in their lives. However, there are other health concerns that are more immediately life-threatening to Aboriginal people. In this regard a health care provider says, “...when one has to weigh how you target your human resources or material resources...I think first of all you have to ensure that you address issues which may be immediately life threatening...it is not that Type 2 Diabetes is not life threatening...but I think when I had a choice of intervening with respect to family violence, substance abuse, unemployment, food insecurity, alcoholism and so many other issues...then I do that first, and then deal with chronic health issues, like diabetes.”

Social factors such as unemployment, not having enough money for food, housing problems, and homelessness--these are viewed as priorities over physical illnesses such as diabetes. Following Galtung's (1980: 67-68) analysis of the 'structures of imperialism', Smith (1993: 44-45) in his work on 'the Eskimo Disk List System' proved that *net effect* of the Eskimo Disk List played a structurally violent role between Eskimos and the larger Canadian social system. In the same way, we can say that diabetes appearance is a cumulative effect of unemployment, unequal accesses to food, housing etc among the contemporary urban Aboriginal people. Those are, again, the results of political, economic and social structural relations between Aboriginal people and the larger Canadian social system, which for them can be seen as structurally violent. It is violent, because it substantially affects peoples' quality of life that may be cause serious illness or death. As one of the health care provider says:

...I think we have to go back to the roots, where they are all stemming from...I have seen there are street peoples who are diabetic and constantly you know at risk of amputation from diabetes, and you know when you are living at a shelter and eating at a mission it is hard to look at issues like diabetes.

There are simply more immediate concerns that people may face on a daily basis; that in turn influences diabetes management and prospects of long term consequences of diabetes. These are the challenges people face in terms of coping or living with diabetes.

Managing or Coping with diabetes:

Coping with diabetes and its proper management is regulated by various individual level or community level factors. Medical professionals, care givers and non-diabetic community members are of the view that ultimate responsibility for control over

diabetes and its management depends on the patient. In this regard, an Aboriginal researcher gave a very practical example. According to her, “if someone is in a meeting and he is diabetic...no body says ‘stop the meeting...it is noon, he has to eat.’ So it is up to the individual diabetes patient to be prepared for the inconsistencies of daily life.” However, discussions in the previous sections also indicate that the causes and consequences of the diabetes are rooted in social circumstances; therefore it is crucial to understand what are the contemporary social and cultural circumstances that make seemingly simple life style changes so difficult for some people. It is also important to understand what motivates them to seek medical help as well as what regulates their lack of lifestyle choices around diet, exercise and stress.

Lack of Dietary Choices:

At both the professional and lay levels it is accepted that the most difficult thing for most people is to implement and maintain dietary changes. “Exchanges and offering of food as gestures of hospitality are integral to the social fabric. Gathering together to eat is a demonstration of friendship” (Joos 1984: 230). But we also know that foods available socially are not always the best choice to eat for a diabetes patient.

...If there is a potluck lunch, no body says..., ‘Hey let’s have a whole lot of food for the diabetic, we have a diabetic here.’ Nobody does that, even though we are very aware of diabetes.

...Restaurants are not geared for diabetic...they sometime call diabetic plate, so you order a salad and there is no food value. There is lot of green stuffs and that is good for you, but there is nothing to balance your food needs.

On the other hand, the way some people express their frustrations around diet suggests that there are deeper links between the affordability of healthy food and dietary choices. One diabetes patients says:

...you don't have money for this, for that, to do this and that...you know I want to buy so many things, but I can not afford to do that. I can not make ends meet till the end of the month to make sure I have foods...because once I pay my bills and rent and what is left over, that's it...you know...I am in a set income. So I have to manage everything out of that. I don't know whether it is on the diet or not on the diet. I just cut down, that is all I do.

The above comment seems very similar to the comment a doctor made. She said,

“...I have patients who have food security issues and diabetes. To me that's a crime, so I can't put them on certain medications and they are going to the food bank and you know, it is just impossible, even if they are totally motivated to manage diabetes. It is really hard to get the food supplement; even if people do have the supplement they don't have adequate money for housing, they have other family members and dependent children. So they are not going to spend all on their diet.”

Again, diabetes control is especially challenging for the people who are dealing with alcoholism. I personally did not encounter any diabetes patient who is also alcoholic. But front line health workers and medical professionals did mention that this is an important issue among urban Aboriginal people, particularly among those who are living on the street.

As a front line worker, I think when there is an alcohol abuse everything just falls off. I mean if you are abusing alcohol and you are diabetic you are not going to be taking your blood sugar level... you are not going to be concerned what you eat and how much physical activity you do...again I think all of that just falls off the map when there is alcohol abuse. You know when you are living on the street; you cannot take care of any of them. How do you manage when you do not have a home...you are living from minute to minute? And eating, you know eating is so important for diabetics...you have to eat regular meals, in smaller portions.

Lack of Choices for Physical activities:

Traditionally for Aboriginal people, physical activities were an integral part of their everyday lifestyle. But changing lifestyle patterns in fast paced urban centers leaves very little or no place to do physical work. Here the only option is to take part in routine physical activities. During my interaction with urban Aboriginal people, it was clear that both as a means of weight control and as a means of reducing health risks, physical activity is clearly recognized as important in the contemporary context. Taking part in physical activities is also challenging for these people. The big problem for many, as discussed in the previous section, is the restricted choices for physical activities. Even walking, which is increasing in popularity for everyone, regardless of age and sex, is burdened with all sorts of difficulties. As one diabetes patient said,

...Right now, no physical activities, because I have a bad leg problem; I tore my ligaments in my knee two years ago. I have been having problem with my sense. But before that I used to do my yard and planting, and I walked quite a lot but I can't do that now because of my leg.

One medical professional explained:

...I also think that exercise is just as important; it's as just that people don't relate it to the diabetes, but I mean for sure the ability to access the healthy exercise, like having the time and the financial resources for healthy physical recreation is also a problem.

However, it is very true that the opportunities for exercise among the elderly or infirmed are quite limited. One person explained that she likes to take part in physical activities but that transportation is the biggest problem, and expense is also an issue. She avoids taking part in any evening activity program, because of her vision problem. Many

urban Aboriginal older people find themselves homebound during winter times. On the other hand, for professional urban Aboriginal people, access to and expense of physical activity programs are not so much of an issue, but they do have time constraints. As diabetes patients say:

...you know my time is tight...but right now I have some times during weekends to exercise. But I really try to be active. Through exercise I try to manage my stress also.

I try to maintain healthy lifestyles...although it is not always possible with the hectic lifestyle. I exercise and take care of myself.

The above discussion indicates that there is a range of barriers both at the individual and community levels that might prevent people to manage or cope with the disease. It is also particularly difficult for women in family settings with a lot of dependents, and when they have a notion that family is much more important than individual; then to single one self out to have a special diet or exercise plan for diabetes would be most unrealistic. According to a front line health worker, stress in relation to diabetes is fairly undervalued in research and literature. More research works need to be done in regard to stress and diabetes. She also says that if as a mother some one knows that her children may develop this disease, then that puts on tremendous stress. Lack of opportunity, poverty, lack of education, health risks all put Aboriginal people at risk.

Lack of Treatment Choices:

Almost all the diabetes patients I interviewed in Small Town, Ontario depend on biomedical treatment. Among the eight patients, all but one rely on oral hypoglycemic or insulin injections to help control their blood sugar levels. Only one person said that she sometimes would go to the doctor for diabetes, but she thinks that the doctor's advice

does not help her to reduce her blood sugar level, so she relies on naturopathy. Interviewees, such as, community members or non-diabetic Aboriginal peoples have also shown their primary reliance on biomedicine.

The limited references to traditional medicine, however, do not necessarily indicate that many more Aboriginal people are not exploring traditional medicinal approaches. It may be that some people were reluctant to discuss traditional medicines with outsiders, as reported in the Regional Health Planning Study (Kapashesit 1997, cited in Abonyi 2001: 164); or perhaps in my limited interviews I simply encountered people who have a primary reliance on western bio-medicine. The groups of people I have interviewed either belong to a working class background, and are relatively young, or are from an older age group. For working class people, it is easier to look for a family physician close to their work place or close to their place of residence in order to accommodate their tight everyday schedule. Such people also have a relatively long history of urban living by being born in this city or having migrated here at an early age. So there is a possibility that they may have less connection or affiliation towards traditional culture and treatment. On the other hand, people from the older age groups may primarily depend on western biomedicine because of its easy accessibility in urban settings; also when physicians, dieticians and foot care specialists are all under one roof in a medical center that is much more preferable for them. Some of the older people said that they do take part in traditional ceremonies as part of the healing process. Olivia, who is now seventy-seven years old, said that she goes to a local Aboriginal health center occasionally, which is the only urban, Aboriginally based, non-profit health center in Small Town, Ontario. There, they do smudging and circles. During my interaction with

an Elder, who is also an Aboriginal healer I came to know that he always gets a good number of participants in his diabetes courses from Aboriginal as well as from non-Aboriginal background. On the whole, people expressed various levels of interest in terms of seeking help from traditional medicine. As Warry (1998: 113) points out, faith or beliefs in Aboriginal health systems are hardly uniform or universal in Aboriginal communities.

It is true that very few people manage their diabetes by diet and exercise alone. As I mentioned earlier, of eight patients I have interviewed, all but one is dependent on either oral hypoglycemic or insulin injection. But I have also found that patients from younger age groups are very serious about their diet and exercise. It can be said that they are managing their diabetes by diet, exercise and medication. Following comments are indicative of that.

During working hours I just stand up and do gentle movement...sometimes take break and exercise upto the point that does not bother me.

...oh, yes, life style changes have been just primarily the diet and exercise...I try to make sure that I am on good diet and exercise.

I am always concern about diabetes because of my Aboriginal ancestry...I watch sugar intake, check my diet, try to stay active.

On the other hand, patients from older age groups are also dependent on biomedicine, but they are trying to control their diet and to be involved in physical exercises that are complementary to their socio-economic conditions. For most of them apart from medication, diet and exercise are also affected by other socio-economic factors, as we have seen before. Treatment and medication are covered by the status card or provincial health insurance or employer provided health insurance. But leisure time

activities or physical activities are not available free of cost nor covered by any type of insurance. At the superficial level, it may be true that diabetes can be prevented by individual lifestyle choice, but actually it is not the matter of choice, it is the matter of lack of choice that can be seen as one manifestation of structural violence. Therefore it is not surprising that some people express a belief that medications without lifestyle changes will control diabetes. During my interview with one patient she said that:

...I know I have to eat little bit of this and that and smaller portions. Sometime I get up in the morning and I don't eat food...I take my breakfast and my lunch together and I take my pills. I can't eat in the morning any more...I don't feel like eating.

This is perhaps because symptoms of diabetes may come and go (symptoms can be suppressed for time being with medications and it may recur again), and sometimes diabetes is asymptomatic, but when there is no immediate complication from diabetes then it is hard to keep it in the forefront of peoples' understanding unless there is any pressing outcome. From the Aboriginal peoples' perspective, the primary goal of treatment may be regulation of immediate symptoms if there are any, whereas from the biomedical view the primary goal of treatment for chronic diseases such as diabetes is to prevent the long-term consequences. But, at the same time, I found that people complain about the mode of treatment and lack of information being provided on long-term complications of diabetes. One patient said:

...they just say you get this, so you got to do this. But eventually if you don't take care of this, you are going to get this...you lose your eyesight...things like that. But they don't really touch on it. I got some brochure from an Aboriginal health center, but there is not much at all. They are giving more emphasis on immediate complications, not on long term consequences.

Another patient also explained similar kinds of experience regarding treatment choices, said:

...they will look at my book and ask if there is any problem...no...okay...see you in three months. My girl friend lives down stairs...she has got diabetes...she goes to a foot specialist. I said no body looked at my feet.

On the whole, the presence of the western biomedical regime as a treatment of choice among the urban Aboriginal people is overwhelming. Some people do have reliance on traditional medicine at a minimal level, but that can be seen as a complementary and parallel system of health practices to western biomedicine. People did not express any definitive interest in the integration of western biomedicine and traditional medicine. On the other hand, at the professional level, people placed reliance on the integration of the two systems, and most of them said that these two systems are complementary to each other in terms of individual usage of those kinds of medications, but they are not in terms of health systems. More precisely they mean to say that selection of treatment choice lies on individuals and both the western biomedicine and traditional medicine can complement each other, though their mode of treatment is independent on its own right. And they think that a co-operative model of health care can work well in this urban center, where they can find the general practitioner, nutritionist and traditional healer in the same building. This center will run in co-operative fashion where the members have full ownership and control over the whole thing. In this regard, health care professionals have also expressed concern about the difficulty of locating credible Elders in an urban setting. One practitioner said, "Western medicine has some useful tools to offer...I share some tools like glycemic index ...I mean some medications are useful...but again, I think there is certainly a role of bringing together Elders, but if

you look at urban community...to actually identify credible Elders, depending on your criteria, could be quite difficult.” But the issue of traditional medicine and believing in it has a spiritual base. These belief systems provide enormous amounts of support and strength when there is a crisis.

Support Systems and Education Strategies:

From the discussions outlined in previous chapter it is clear that diabetes is an everyday battle that needs a tremendous amount of care and support for its prevention and management. In my view, support systems currently in place in Small Town, Ontario meet the needs of Aboriginal peoples to some extent. There is only one Aboriginal health center situated in this city, which is for different practical reasons (distance, lack of information, transportation) not always accessible to all Aboriginal people. On the other hand, the public health system is not geared to provide Aboriginally specific health care and support. This discrepancy arises due to the differences in perception between the Aboriginal diabetes patients and medical professionals.

The following discussions reflect that primary sources of general support are family and friends, while professional sources of support are regulated by a complex public health care system.

Informal Diabetes Support and Care:

The stories I have heard showed that the most significant sources of support for people with diabetes are families. Family members provide tremendous amounts of support and assistance in getting through the simple day-to-day activities that become

more challenging for a person with diabetes. Philip shares his feeling about the care and support he gets from his wife. He relies on his wife for his foot care. He has ulcers in his feet and every morning his wife has to treat them. He says that if she is not around he has to go to a clinic to get that done.

In a similar way, efforts to maintain a healthy dietary intake to a great extent rely on support from friends and family members. Issac said that his fiancé was very supportive from the time he was diagnosed with diabetes in terms of getting a healthy diet, taking his pills in a timely fashion, and doing exercise. His sister-in-law is also very supportive for him. He said that whenever they go to United States, they bring back good diabetic grocery things, because in the United States things are a lot better than what is available in Canada.

Mary-Ellen remembers that when her grandpa was diagnosed with diabetes, pretty much all of the family members changed their lifestyle in order to accommodate him. She also remembered that they all helped him in adopting diabetes-friendly lifestyles; otherwise she thinks it would have been difficult for him.

As we mentioned earlier, both health care professionals and Aboriginal people accept that the ultimate responsibility for diabetes care lies with the individual, but the above comments reveal that family plays a significant role in terms of diabetes management.

In contrast to the above instances, there are Aboriginal diabetes patients who think that they do not have the support of their families. I found some people who are in an older age group (over fifties) living on their own have very less family support. They primarily depend on the public health system to provide care and support. Olivia,

seventy-seven years old, said that she has ten children, but they are all over the place. She has no contact with them. She lives alone. For her diabetes treatment and care she goes to the clinic.

Formal Diabetes Support and Care:

Like any other city, the one we examined has a range of medical professionals who provide diabetes management, education and prevention strategies for patients. They range from medical doctors, nurses, dieticians, diabetes educators, and health promotion workers to health directors. During my interviews with representatives of these health care providers, I found that there are varied perspectives on health and experiences of diabetes.

Persons who have developed diabetes or are at risk of developing diabetes usually start getting their formal medical support from a physician's clinic. During my conversation with a family physician, she said that in her clinic, after diabetes is diagnosed she would get her patient to stop excessively sugary food and would refer the patient to a dietician at the local Aboriginal health center or at some other local centers. They might be put onto oral medication or insulin depending on their sugar level. She will definitely give importance to physical exercise. She might also refer her patients to the local Aboriginal center diabetes group.

In terms of referring them to Aboriginal centers, she found a problem of identifying their Aboriginal ancestry. She says, "here the majority of Aboriginal people would have family doctors; right? And I think many of those doctors may not identify that the client is Aboriginal. That is another thing I find in this urban environment. At

least fifty percent of Aboriginal people who are not at an Aboriginal health center would not have gotten to identify...so...what people look like in this kind of urban environment is really a bad indicator of their ethnicity in terms of Aboriginal heritage.” She also said that most of the time she found that unfortunately patients do not keep up-to-date with their follow-up visits, therefore it is not possible for her to monitor their progress, and to support them in terms of any kind of lifestyle change that might be needed.

Overall, medical professionals do agree with the holistic philosophy of health. They also agree that seeking medical help, or motivation to seek medical help also depends on where people are at socially, emotionally and economically. According to them, there are often more immediate pressing issues such as housing, unemployment, food insecurity, substance abuse, that may take priority over diabetes management.

In the course of my interviews with a registered nurse who has several years of working experiences with Aboriginal people in different parts of Canada, but is now attached to one of the local hospital based care facilities, I found that her frustrations are similar to those of other health care professionals. She is familiar with the incidents of no show-ups during follow-up sessions, but at the same time she recognizes that these behaviours are rooted in the range of daily obstacles that these patients experience. She identifies diabetes as a major concern among urban Aboriginal people in this region, but immediately adds that mental health and socio-economic issues are more immediate priorities for them.

In regard to diabetes education programs, both health care providers and front line workers agree that the education and prevention programs that are being provided in this city, apart from the Aboriginal health centre, are not well-designed for Aboriginal culture

and their present social circumstances. The effectiveness of Western ways of teaching in different diabetes workshops may also be compromised as a poor fit with the Aboriginally specific teaching style. One front line health worker says, “you know Aboriginal people are very visual people. If you give them a book and ask them to read it about diabetes that would not be effective for them...if you say, ‘look this is a can of coke and this contains twelve tea spoons of sugar, then when your son comes home and he has got a big bottle of coke from Seven Eleven...and you know there are forty eight tea spoons of sugar’...this is more visual for Aboriginal people...usually I see in the workshops, there are lots of slides, pamphlets, lots of reading and patients are being tested in front of others (lack of privacy) are just not appropriate for Aboriginal culture and their people.” She also mentioned that in terms of teaching tools, lack of information and sensitivity towards patients are very prominent. Aboriginal ways of teaching are that Elders talk and others observe, and there is a lot of role modeling and social reinforcement there. There is clearly room for culturally appropriate methods of teaching by community Aboriginal Elders or knowledgeable persons.

Other kinds of support networks:

Besides formal and informal support networks, patients still want to talk to someone who is suffering from the same disease or feeling the same way they feel. Some people like group discussions. One lady says:

...in group discussions...sharing knowledge is very important. If we are in a group and someone says something, then I will say that...‘oh, I don’t have that... I don’t have this...I didn’t know that’...then I can ask my physician next time when I go see him.

A medical professional made an important comment in regard to group discussions. She said that she is not sure whether the groups are always the best because people may do better with one-on-one teaching depending on what their issues are, and in any case learning styles are different. According to her, the individualized support system is the best option.

As we have discussed, for everyone at community level, patients or non-patients, lay and professionals, there is consensus that diabetes is one among many other concerns. It was mentioned that medical professionals express the holistic philosophy of health, which is comparable to Native Medicine Wheel. But current education, prevention and support strategies do not reflect the underlying factors that are making diabetes management more challenging for Aboriginal people.

Intervention is needed with diabetes management on a larger level and requires a different approach. It begins with recognizing that diabetes as a disease is related to underlying social problems that are legacies of a colonial past. Some of the lifestyle choices around diet and physical activities which lead to obesity and diabetes have their origins not only in contemporary crisis of cost, availability, access and opportunity but also in lack of pride and dignity in their own culture and language. Abandonment of traditional ceremonies and medical practices may have contributed to personal degradation among the Aboriginal people. One Aboriginal Healing and Wellness program co-ordinator says, "Aboriginal people, whatever nations, belief, language or ancestral connection you have; if as an individual you can take it upon yourself to research your identity to reinitil the pride and dignity of knowing who you are and recognize that what is important in life is the continuation of what life means to us as

human beings; but we also can educate the forthcoming generation, so that we will be able to pass on that awareness to the future generations, to a more healthy and positive lifestyle.” These perspectives suggest that renegotiation of identity at individual and community level, and resurgence of cultural traits can play a central role in the production of healthy Aboriginal people. As Manuel (1970 214-266) envisioned the resurgence of self-confidence for Aboriginal people in his ‘Fourth World’ concept; and that this has to be integrated in the restructuring of health strategies.

Summary:

Much of what has been understood from our interviews with Aboriginal people indicates that the pattern of diabetes emergence as a disease is quite similar to that described by other researchers for Aboriginal Peoples. Diabetes is a recent feature in the memories of health and sicknesses of these urban Aboriginal people. Discussions of Aboriginal diabetes in the literature focus on lifestyle changes, more precisely on changes in diet and physical activities. It is clear that childhood memories of these people witnessed the shift towards permanent settlement in communities and also brought with it the kind of lifestyle changes found in other North American Aboriginal communities. From their memories of the past, people talked about reduced access to land resources, increased reliance on market food, reductions in physical activities, poor housing conditions and the legacy of residential schools with reference to changes in lifestyle, and their consequences for the appearance of Type 2 Diabetes. It is true that residential schooling system is one part of displacement of all of the structurally violent relationships resulting from colonialism and assimilation policies. But the details of

change in diet and physical activities go beyond the historical documents, and the structurally violent relationship of Aboriginal people with the broader social system that produces restricted lifestyle choices is very much prevalent in the present day situation. In this regard, diabetes emerges along with poverty, food insecurity, lack of education, unemployment, alcoholism and so many other socioeconomic factors as a challenge to these people in this urban setting.

More in-depth analysis reveals that though there are differences in dietary choices for men and women, significant differences lie in physical activity patterns. Women are less physically active than men starting from early adulthood through childcare years, which may account for differences in overweight and even diabetes prevalence in men and women. The residential school experiences have had a significant effect on the diet and other aspects of family. People commented on the lack of parenting skills and expressed frustration in terms of having limited culture-specific experiences to share with their children. Much of the explanation for contemporary lifestyle patterns of these urban Aboriginal people can be located in socioeconomic conditions and in the demands of a western sedentary lifestyle.

Analysis of the perception of diabetes and its causes suggest that diabetes is attributed to circumstances imposed by white men. Diabetes is of great concern among Aboriginal people, but sometimes if the disease is asymptomatic and there are no immediate complications it is hard for people to keep it in the forefront of their understandings. Similarly, barriers in dealing with diabetes, both from the prevention and management perspectives, include more immediate concerns such as poverty, education, unemployment, housing, economic and social relationships. Both at the professional and

community level these factors were identified not only as barriers, but also as the root causes of individual and community problems. Aboriginal people in this urban setting, regardless of their physical condition, clearly have a good understanding of diabetes management strategies. They are coping or managing diabetes in a way that is complementary to their socio-economic conditions. Diabetics and non-diabetics both accept that in spite of the crucial role that families play in terms of diabetes treatment and management, the ultimate responsibility of lifestyle choices rely on individual. Medical professionals also hold similar ideas about diabetes management. At the same time, everyone is aware that these simple lifestyle choices about physical health are deeply affected by circumstances of history, economy, society and family.

Chapter 5

Summary and conclusions

Prior to this project, there had been little or no systematic collection of knowledge on urban Aboriginal peoples' perception and experiences of Type 2 Diabetes in this Small Town of Eastern Ontario. In this final chapter I want to review some of my key findings, delimit areas of this research, highlight some areas of future research and policy implications.

This thesis started with research questions that included "Why are Aboriginal People contracting diabetes at a higher rate than the rest of the Canadians? How do Aboriginal people, especially women, perceive the risk of contracting Type 2 Diabetes Mellitus? What are the characteristic ways in which Aboriginal people cope or manage the consequences of this disease?" The contribution I offer here with this thesis is an exploration of diabetes as a human problem that is being shaped by various determinants of health (e.g. social, cultural, historical) offers serious challenges for today's Aboriginal people. My aim was to identify the processes that have given this metabolic disorder a socially recognizable meaning.

My immediate objectives included:

- To locate diabetes in its social, cultural and historical context in order to better understand its emergence among Aboriginal people.
- To explore the perception of diabetes and its management among Aboriginal people.
- To identify the lay and professional perceptions of diabetes with reference to its

prevention and management.

Key Findings of the Research:

Aboriginal people understand the emergence and causes of diabetes in a number of ways. The link between diabetes and westernized lifestyles revalues the health benefit of a traditional lifestyle. Diet is a particular concern among the community people, as well as among medical professionals. The explanation of unhealthy diets lies partially in the high cost and availability of appropriate foods. This issue is also supported by health care professionals who agree on the role of the economic burden of unemployment, poverty and food insecurity. The traditional modes of subsistence and food procurement are no longer feasible in this urban setting. Therefore it is suggested that the explanation is located in socio-cultural factors that include low self-esteem, lack of pride and dignity or frustration with poverty and issues such as those experienced in the contemporary context. But these behaviours can also be traced back to the isolation (reserves) and assimilation (residential schools) processes Aboriginal people are still going through historically.

Diet, physical activity and stress, are the three triggering factors identified by community members and medical professionals that work behind the emergence of diabetes. It is also brought to attention that women tend to carry an extra burden of stress, have fewer physical activities and have compromised healthy diets in this fast pace of city life. The difference begins early in childhood and continues through the childcare years. Women have fewer opportunities than men to pursue physical activities. Community activities are also limited for women because there are few activities that

accommodate the presence of children. On the other hand women are the ones who balance their families' diet on a restricted budget, since most of the Aboriginal families are living in substandard financial strata. As care-givers they always put themselves last and feed the rest of their family members first. All of these complex life situations place extra stress on them. Stress levels vary depending on the socio-economic background of women. All these three triggering lifestyle factors may suggest differential weight gain patterns among men and women, and perhaps account for increasing prevalence of diabetes among women.

On a general level, the people of this urban setting lead a diabetogenic lifestyle characterized by a higher concentration of fast food, canned food high in calories and a sedentary pattern of city life. Explanations can be located in socioeconomic conditions (poverty, high expense of food) and the demand of late twentieth century lifestyle (e.g. sedentary work). This research also indicates the role of colonialism in creating contemporary conditions. Aboriginal people throughout Canada share a colonial experience that gives rise to the issues of lack of pride and dignity, low self-esteem and low self-worth among themselves. This is visible at every level of contemporary life, which again provides some explanations about their diabetogenic lifestyle.

At the community level, for some of the diabetic and non-diabetic community members, diabetes is perceived as normal for Aboriginal people. While for others, initially, the diagnosis is a shocking experience. They blame themselves for not being able to follow traditional lifestyles, and express frustrations with contemporary limitations in everyday life. Health care professionals feel frustrated when there is discontinuity for regular check ups, but they do appreciate the importance of immediate

and more pressing issues of everyday life. Again, diabetes to some extent may be asymptomatic, or its symptoms may just come and go. Therefore, from the patients' side, medical help may be taken only when symptoms are visible. But there is a marked difference in terms of patients' socio-economic backgrounds. Patients from educated professional background who participated in this research express serious diabetes control and management strategies, while others belonging to relatively lower socio-economic strata manage or treat diabetes depending on availability of resources.

Since in the case of diabetes diagnosis is not always accompanied by immediately noticeable symptoms or complications, it may also affect how maintenance of physical health is prioritized. This could mean that focusing on one aspects of life (e.g. social, cultural and economic) takes precedence over and compromises complete physical health. Priorities for many pressing aspects of life include overwhelming challenges such as substance abuse, housing, education, employment, poverty, and food insecurity.

Current levels of diabetes and management strategies, including treatment, support and education meet these urban Aboriginal peoples' need only to some extent. It is also unarguably true that ultimate responsibility for control over diabetes and its management relies on patients and their family members. This public health system fails to provide aboriginally culture-specific care and support. There are also no structured connections to the psychological, social, and economic sources of support that might help diabetics to deal with their disease in a more effective way. Discrepancy arises due to the differences in perception and experiences of diabetes between individuals in the community, between diabetics and non-diabetics, between youth and the elderly, between poor and affluent, and between health care professionals.

Delimiting Research Areas:

About fifty percent of Canada's Aboriginal population lives in urban centres, with many Aboriginal people living in the larger urban centres. Urban Aboriginal people face challenges well in excess of those of the non-Aboriginal urban population on a number of important indicators of personal and community well-being (Privy Council office 2003). Literature also indicates that there are large numbers of Aboriginal homeless in Eastern Canadian cities (Beavis *et al* 1997). Therefore it is important to include the experiences of Aboriginal people who are homeless or living on the street, as this group of people are at great of risk of contracting diabetes because of their unhealthy diet, life style pattern and lack of lifestyle choice. Again management and treatment of diabetes is also challenging for them because of their living conditions.

My research was conducted among Aboriginal people living in Small Town, Ontario. The socio-demographic structure of Aboriginal people living in this city represents a sharp divide between professionally educated Aboriginal people, and the people living on the street or the homeless people. There is another category of people with limited resources who fall in between these two extremities. In order to present an ever-encompassing view of diabetes perceptions and its management among urban Aboriginal people, it is extremely important to include research participants from all the different socio-economic groups. Unfortunately it was beyond the scope of this research to include homeless or street peoples' perception about diabetes and its management. I know in a sense this research leaves out a whole range of people that are really visible and important in this urban world, who are struggling day by day and who also have the

greatest risk in regard to contracting diabetes due to their unhealthy lifestyle choices, but wherever possible I have presented life situations of urban street people from the conversations I had with health care professionals as well as from published sources.

At the community level, my research included the views of health care professionals, educated urban Aboriginal professionals and people with limited resources (these people are reliant on old age pensions, social assistance, etc) regarding perception of diabetes and its management. I believe it is also extremely important to explore how Aboriginal People regardless of their diagnosis with diabetes, who are moving into a professional world, and others who are surviving on limited resources in this urban context are proceeding and acting upon their responsibility of diabetes. Likewise it is mandatory to acquire health care professionals' perceptions about diabetes and its management that can provide a complete picture of urban Aboriginal diabetes.

Future Research and Policy Implications:

While I feel I have managed the primary objectives set for this study, I am also left with the knowledge that I have only just begun to understand the implications of the findings. On a practical level, priority should be placed on the collection of up-to-date, regionally specific health statistics, particularly on diabetes prevalence. It is also important to carry out an analysis of the quantities of food consumed at different meals, as well as more detailed analysis of gender differences in food consumption. This may clarify the remarkable differences that lie between the sexes. I have presented some opinions on the basis of qualitative information I gathered from the health care providers and community people. But, in this case a rigorous quantitative analysis is needed.

Overall the health status of urban Aboriginal people, specifically women's health should be given priority with the identification of the most pressing program and policy needs of this population.

It will also be important to carry out research on indigenous perception of diabetes prevention or what one should do to avoid getting this disease.

It will be valuable to include more diabetes patients from different age groups in order to get more varied experiences. As health care professionals witnessed, the age of diagnosis is decreasing, therefore it will be necessary to include research participants from as early as eighteen years of age in order to deal with earlier adult-onset diabetes. It is also important to explore people's perceptions of diabetes and its coping strategies according to different age groups, gender and socio-economic strata. Research related to these areas should be funded as a basis for the development of health programs and policies directed specifically toward urban Aboriginal people.

It is also important to develop a systematic study comparing rural-urban differences in diabetes prevalence and peoples' perception regarding this. At the policy level priority must be given to differential experiences of First Nations, Inuit and Metis female. To develop a database on urban Aboriginal health and health determinants would be very important to work on.

It is extremely necessary to devote the research attention to the problems facing urban Aboriginal street people or homeless people with diabetes, so health promotion programs will enhance their quality of life through improved service delivery.

The cross-cultural study about perception of diabetes among Indigenous groups in Canada and elsewhere can be undertaken as a foundation for international bridge building

and collaboration among the various Indigenous organizations.

A close consideration of the reorganization of health strategies towards the treatment of diabetes among other Aboriginal communities and further integration of these strategies into provincial and federal health policies would be important to carry out.

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