

ABORIGINAL AND BIOMEDICAL PERCEPTIONS OF DIABETES

ABORIGINAL AND BIOMEDICAL PERCEPTIONS OF
NON-INSULIN DEPENDENT DIABETES MELLITUS (NIDDM)
ON MANITOULIN ISLAND

By
JULIE SUNDAY B.SC.

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AUTHOR: Julie Sunday, Honours B.Sc. (Carleton University)

SUPERVISOR: Professor John Eyles

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ABSTRACT

This study is an exploratory qualitative analysis of Aboriginal and biomedical perceptions of non-insulin dependent diabetes (NIDDM) on Manitoulin Island. In-depth interviews were used to explore perceptions of the symptoms, causes, cures and consequences of diabetes amongst both health care providers and community members. An equal sample of individuals both with and without diabetes were interviewed.

This study attempts to highlight divergent perceptions of NIDDM on the part of community members and health care providers. It argues that these perceptions are linked to divergent conceptions of health. Specifically, community members describe health in terms of cultural identity and social resilience. In contrast, health care providers focus on the physical dimensions of health and emphasize individual responsibility in maintaining health. As such, both biomedical and community narratives are engaged in the process of defining 'normality' within these divergent frameworks. Implications of these perceptions were explored in relation to diabetes management and treatment; causal factors; and emergent definitions for the 'body'.

Attitudes towards diabetes 'management' differed between health care providers and community members. Health care providers related 'poor' management to a lack of compliance with lifestyle recommendations whereas community members describe barriers to management despite an articulated desire to do so. Within a biomedical framework, the diabetic 'self' has a duty to act responsibly and manage their diabetes. The measurement of the blood sugar level is a marker of responsible actions.

Nonetheless, community narratives emphasize the social and emotional consequences associated with managing diabetes thus highlighting how *certain* selves are better able to ‘manage’ diabetes than others.

Divergent causal stories were outlined by health care providers and community members. Biomedical narratives emphasize the importance of individual lifestyle factors, particularly the impact of obesity, in causation. In contrast, community narratives emphasize the role of genetics in causation. Community narratives describe diabetes as *collectively* affecting Aboriginal people – further identifying those affected as *different*. Within this framework, the biomedical focus on modifying individual lifestyle practices is questioned and the pursuit of health becomes contingent on returning to an initial state of purity and health through traditional knowledge.

Definitions for a ‘healthy body’ were also redefined within community narratives. It was argued that the emergent definitions can be considered a form of resistance – to both the universal body of biomedical discourse and the universal ‘Native body’. Specifically, this resistance was expressed in definitions for causal factors describing an essentialized ‘Native body’ that is genetically and psychologically distinct. Nonetheless, a minority of community members also expressed resistance to the concept of a ‘Native body’ that is genetically distinct. Additional resistance was evident in narratives describing the relationship between health and body size. Within these narratives community members describe a healthy body that is larger thus questioning the biomedical emphasis on the relationship between thinness and health.

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- These are my favourite lines. I'll whisper them. "I have taught you that the sky in all its zones is mortal....Let me now re-emphasize the extreme looseness of the structure of all objects."

Michael Ondaatje *In the Skin of a Lion*

"There are times in life when the question of knowing if one can think differently than one thinks and perceive differently than one sees is absolutely necessary if one is to go on looking and reflecting at all."

Michel Foucault *La Volonté de Savoir*

Prologue

*“So we sit
Within loose walls of the poem
You and I...
All of us searching to discern ourselves,
The ‘gift’ we can give each other.
Tell this landscape.
Or the one we came from”.*
Michael Ondaatje

Re-reading this poem, I was reminded of a conversation that I had following the presentation of some of the results of my research to the UCCM Mnaamodzawin Health Board. This conversation was with Marjorie Shawande, the Traditional Coordinator for Noojmowin Teg Health Centre. Marjorie asked me a simple question, but one that none of the books that I had spent my time with over the past year were going to ask me. She asked: “What have you learned?” - a question that brought this research out of the library and grounded it in the personal spaces of my own life. I realized that in becoming pre-occupied with the ‘findings’ of the research, my own place in this learning got lost. Feeling myself settling into the ‘expert’ constellations that make up the academic map, Marjorie reminded me of my role primarily as a *learner* - a commitment that stretches beyond the thesis. In broad terms, the narratives in this thesis have helped me to understand how diabetes is linked to the social, political, cultural, and economic environment in which it exists. Specifically, these stories bring to life the relationship between the body and society. The process of researching and writing this thesis has essentially been about discerning the landscape that I come from in relation to the landscape that I have been provided with glimpses of through the gift of people’s

stories. It is hoped that the thesis will have some tangible impact on both of these landscapes - the university and the communities on Manitoulin Island.

The following thesis will outline the results of a qualitative study exploring Aboriginal and biomedical perceptions of non-insulin dependent diabetes (NIDDM) on Manitoulin Island.¹

¹ In other sources NIDDM may also be referred to as 'Maturity-Onset diabetes' or 'Type 2 Diabetes'.

Chapter 1: Introduction

The political will to recognize diabetes as a major health care issue for Aboriginal people in Canada exists at both the national and the local levels.² At the national level, the Assembly of First Nations (AFN) has worked towards increasing awareness, research, and developing strategies to prevent diabetes (AFN 1996-97, 1). These efforts have included the establishment of the National Aboriginal Diabetes Association. Additionally, Canada hosted the Third International Native Diabetes Conference in 1995. According to Kewayosh (1995, 6) this conference was a milestone in the lengthy struggle of First Nations to raise diabetes as a serious health issue of National and International prominence.

This study has focused on the occurrence of diabetes in Aboriginal communities at a local level – specifically, in the communities of Whitefish River and Sucker Creek on Manitoulin Island. These were both Anishnaabe – also referred to as ‘Ojibway’ communities. Both health care providers and community members identified diabetes as the most significant health problem facing these communities. The rate of diabetes was highest in the community of Whitefish River, where 42 individuals out of a total population of 291 have been diagnosed – a rate of approximately 15%. In Sucker

² Following Warry (1998, 263) the use of the term Aboriginal is capitalized in order to “indicate a unique status and unique identity.” Additionally, the term ‘Native’ is mainly used to contrast the term non-Native - referring to “members of the predominant Western culture” (Warry 1998, 264).

Creek, 16 individuals were diagnosed as having diabetes out of a total population of 279 – a rate of approximately 6%. In contrast, the rate of NIDDM in non-Native populations is approximately 2-5% (Young et al. 1990, 129). Among the community members interviewed, the majority identified having individuals in their family with diabetes.

When asked how long diabetes has been around, almost all community members responded that it is relatively recent, specifically within the last 20 years. Community perceptions of diabetes describe it as a contemporary health issue and thus discussion of diabetes is one of the socio-historical changes that these communities have gone through in the past fifty years. This relationship will be elaborated in Chapter 4, for now it will suffice to note that diabetes is largely considered to be a recent phenomenon. As Elaine says:

“Recently there is like an outburst among the natives. It’s all over. Everybody’s getting it.”

A minority of individuals responded that diabetes is not a recent phenomenon, but rather that increased diagnosis is contributing to higher numbers.

Dorothy described this possibility:

“I’m not so sure it’s really gone up. It’s just that maybe now that people have even better access to health services now that they can be diagnosed with those kinds of illnesses or diseases.”

This perspective - that the high rates of diabetes are a result of increased diagnosis - was held by most health care providers. Many described an increase in population size coupled with increased diagnosis resulting in the *perception* of an increase in diabetes.

John described this possibility:

“The literature makes me understand it’s probably been an issue for at least 30 or 40 years. But before that it may have been there but we weren’t picking up on it. Other things were more important, like infectious diseases. Now that we’ve cured a lot of those problem, other problems that have always been there and been a problem are becoming more important. For example, if you’re in Africa dying of AIDS you’re not going to worry about your cholesterol level. Other things take precedence. I would say why we’re seeing more diabetes now, is that we’re diagnosing more, that the criteria of diagnosis has dropped. ...People are more aware of disease. More people are asking to be checked out. Making more diagnosis. Because you make a diagnosis earlier you have diabetes longer, so they’re living in the community longer. The prevalence has gone way up and the incidence has gone up a little bit.”

Within this statement, there is a sense that diabetes is not a recent occurrence but is rather the result of increased awareness and changing health care priorities – specifically, the transition from infectious to chronic diseases. Although the high rates of diabetes are recognized, this statement offers a somewhat optimistic perspective as it describes an overall *decrease* in the disease burden in Aboriginal communities through biomedicine’s ‘curing’ of infectious disease. This statement describes a situation where Aboriginal people have been affected by illness for a long period of time; however, it is thought that improvements to their health status are occurring through biomedical science. Within this framework, it is implied that a solution to the health problems facing Aboriginal communities has come from the health care system. Nonetheless, the position that improved health can be equated with increased health care has been contested by a number of sources (see Evans & Stoddart, 1990). As will become evident in the thesis, this position is also contested by community members.

In sum, community members considered diabetes a recent phenomenon, whereas health care providers emphasized that although it may appear to be increasing,

this perceived increase may be a result of increased recognition and diagnosis. The following section will shift away from community narratives and will outline perspectives in the literature on the observed increase in incidence of diabetes among First Nations Peoples.

Background

Non-insulin dependent diabetes mellitus (NIDDM) has been observed among Aboriginal peoples since the 1940s. Szathmary (1994, 460) describes how two decades ago, the occurrence of diabetes among Aboriginal people was described as “epidemic,” however, a lack of uniform diagnostic criteria made it difficult to verify this claim. Within Canada, a rise in the rates of diabetes among Aboriginal peoples has become noticeable in the past 15 years (Young 1994, 22). Much of the data collected for diabetes has occurred in the United States, where age-adjusted mortality rates indicate that the rate of diabetes is twice as high for Aboriginal people (Young et al. 1990, 129). Less has been published in Canada, however, a study done by Young et al. (1990) indicated several trends. In particular, this study outlined the existence of significant variability in tribal and regional prevalence rates. These rates varied from 0.8% in the Northwest Territories to 8.7% in the Atlantic region (Young et al. 1990, 129). Young et al. (1990, 136) stated that diabetes prevalence is associated with latitude in Canada, and attributed this relationship to shifts in lifestyle occurring along geographic gradients. In other words, the rate of acculturation and proximity to non-Native population influence the

occurrence of diabetes among First Nations in Canada (Heffernan 1995, 267; Szathmary 1990, 460).

Although NIDDM is increasing in all modern populations, the high rates currently observed in Aboriginal populations were unreported prior to 1940. Heffernan (1995, 261) states that the current increase does not appear to be the result of increased case finding as screening urine samples for glucose was common practice before the 1940s. A prevalence study in Ontario and Manitoba described a dramatic increase in incidence among Aboriginal people – where 50% of the cases were individuals diagnosed in the last 5 years of a 25 year period (Young et al. 1985, 796). Although it is recognized within the study that increased access to medical care is partially responsible for these rates, Young et al. (1985, 796) states that a similar increase in other parts of the world points to a general increase in prevalence. Fox et al. (1994, 92) found similar trends among Aboriginal people in North Western Ontario. Outlining the differences between this study (Fox et al., 1994) and a previous study that identified a prevalence rate of 28 per 1000 in the Sioux Lookout Zone area (Young et al. 1994); Fox et al. (1994, 92) reported that, a decade later, the prevalence rate has increased to 38.3 per 1000, where 45% of the cases were diagnosed in the past 5 years. This change in prevalence suggests a rising incidence of diabetes among Aboriginal peoples in these areas.

Additional studies have outlined specific differences between Native and non-Native rates of diabetes within a similar geographical area. Evers et al. (1987, 240) found a non-Native diabetes rate of 2.2% in Southern Ontario – a rate that approximates

the national average (Statistics Canada 1981, 538). In contrast, this study described a prevalence rate of 15% among Native people. These rates are much higher than those reported in the study by Young et al. (1990). Evers et al. (1987, 243) attribute these high rates to the impact of acculturation in this area which is characterized by high levels of urbanization. A further study outlined a prevalence rate among James Bay Cree that is 2-5 times higher than the Canadian population (Brassard et al. 1993, 306). This study also associated diabetes prevalence with levels of acculturation and thus, similarly to Young et al. (1990), identified latitude as a predictor of rates of diabetes among Native populations.

As part of this general increase, particular concern has emerged over the appearance of NIDDM in youth. Of all the forms of diabetes, only NIDDM is increasing in incidence among youth (Rosenbloom et al. 1999, 345). This “emerging epidemic”, attributed to changing food patterns and the occurrence of obesity, is most closely associated with minority populations (Rosenbloom et al. 1999, 345). Within the 5-14 year age group, 10% to 20% of new cases of diabetes in Manitoba were NIDDM and these cases occurred exclusively in the Native population (Dean et al. 1992, 52; Dean 1998, 89; Square 1998, 292). Harris et al. (1996, 869) observed a similar trend in the increased prevalence of NIDDM among Aboriginal youth in northwestern Ontario. The following section will outline explanations for this increased incidence.

Factors Associated with High Rates of NIDDM in Aboriginal Populations

The onset of NIDDM is attributed to both genetic and environmental factors. Much of the literature has focused on the role of genetics in NIDDM due to variation in rates between ethnic groups (Heffernan 1995, 268). Nonetheless, it has been argued that environmental factors have a more significant role to play in diabetes onset and that given the right conditions most populations are at risk (Heffernan 1995, 268). Currently the most plausible explanation is that the increase in rates of NIDDM among Aboriginal people is a result of lifestyle changes since WW2, coupled with genetic susceptibility (Szathmary 1994, 463).³

Several hypotheses have been proposed to explain genetic susceptibility to NIDDM among Aboriginal people. The earliest explanation, termed the ‘thrifty gene hypothesis’, was put forth by Neel (1962) who reasoned that a gene that is now deleterious may have provided a selective advantage in the past. He postulated that in an environment of feast/famine conditions a rapid insulin response to a plasma glucose stimulus would convert excess glucose into fat and therefore prevent energy loss – a selective advantage (Szathmary 1994, 464). Under conditions of constant food supply this quick insulin response would become maladaptive. Following Neel’s hypothesis, a population-specific evolutionary model termed the ‘New World Syndrome’ emerged (Szathmary 1994, 465). This hypothesis postulated that there was a genetically

³ Within this framework, lifestyle refers to nutritional habits and the cultural variables that influence human energy expenditure.

controlled alteration in the pathways involved in lipid synthesis. Similar to the thrifty gene theory, individuals with this trait would have the ability to store fat in plentiful times. Nonetheless, there are problematic assumptions underlying these two hypotheses when applied to a low carbohydrate, cold environment. Both of these hypotheses assume that Aboriginal people lived in a nutritional environment where carbohydrate intake was higher than daily energy requirements. This type of environment did not occur in the arctic and subarctic – the environment in which Aboriginal people originally resided. A third hypothesis was proposed to account for this discrepancy and suggested that if selection favoured genes that enhanced gluconeogenesis, present day carbohydrate rich environments could lead to NIDDM (Szathmary 1994, 466).

Lifestyle factors that may contribute to the onset of diabetes include: dietary change; obesity; level of physical activity; and stress (Heffernan 1995, 268). Obesity is considered to be common in Aboriginal communities and due to the relationship between obesity and the onset of diabetes it is also considered to be a significant risk factor (Szathmary 1994, 472). However, obesity alone can not cause NIDDM (Szathmary 1994, 472). Psychosocial stress has also been identified a risk factor for diabetes due to its effect on glucose homeostasis (Szathmary 1994, 474). Heffernan (1995, 273) emphasized that chronic stress, involving a lack of power and control, is associated with ill-health and therefore may have an influence in the onset of diabetes. Each of these risk factors may promote the emergence of the NIDDM phenotype in individuals who are genetically predisposed. The ‘thrifty phenotype hypothesis’ has been proposed to explain

the emergence of NIDDM under these conditions. This hypothesis postulates that impaired development of the endocrine functions of the pancreas may occur when there is inadequate nutrition early in the lifecycle (Szathmary 1994, 470).

Shifting the Lens: The Role of Social Science in Approaches to Diabetes

As mentioned by Heffernan (1995, 268) an emphasis has been placed on the need to explore the genetic basis for diabetes among First Nations People. A recent *Globe and Mail* article (Abraham, 1998, A1) was evidence of this emphasis, and described a situation where Aboriginal people in Sandy Lake, Sioux Lookout Zone have given researchers samples of their DNA so that they can “unearth the genes responsible for their diabetes”. The high rates of diabetes in this community have been attributed to the presence of ‘thrifty genes’ and therefore this research emerged from the need to:

“Unravel their DNA to find the genes that were instructing their bodies to hoard the calories and sugar...If [the researcher] could find them he could tinker with them and perhaps even find a way to reverse the damage they were causing” (Abraham 1998, A13).

Within this article there is a strong sense that the basis for the occurrence of diabetes is genetic and thus it would be possible to isolate and perhaps ameliorate this causal factor. To provide a sense of the importance of the need to address the problem of diabetes, the writer described the poor living circumstances in this community where:

“Running tap water is a novelty....But it was the sugar disease, *not economics* that required immediate attention.” (Abraham 1998, A1, emphasis mine)

This article creates a clear divide between the occurrence of diabetes and the particular socioeconomic conditions in which it occurs. In other words it decontextualizes the occurrence of diabetes and proposes a solution that is located within a biomedical framework.

Contrary to the position put-forth in this article, much of the contemporary research on population health suggests that factors associated with an individual's place in the social hierarchy are significant determinants of health (see Wilkinson, 1996). Additionally, the ability to partition populations in a way that defines subgroups that differ systematically in health status suggests that social and economically structured life processes are most influential on health (Hertzman et al.1994, 75). Travers and Paul (1995, 37) have referred to this increased occurrence of diabetes among First Nations People as an indicator of a "health inequality". Stating that genetics alone cannot account for the variance in prevalence rates between Native and non-Native populations, Travers and Paul (1995, 37) argue that the occurrence of diabetes is most closely associated with social factors (i.e. sex/gender/class). Diabetes in First Nations communities can thus be related to inequitable access to resources that are supportive of health – otherwise termed a 'social inequity'. The relationship between socioeconomic status and diabetes has also been demonstrated in studies for the prevalence of NIDDM among Mexican Americans (Stern et al. 1984, 834).

The possibility for the social, political, and economic landscapes to create barriers that prevent certain individuals from living 'healthy lifestyles' and managing

diabetes is reflected in this occurrence. According to age-adjusted mortality rates, NIDDM has become a lethal problem among Aboriginal people in North America (Szathmary 1994, 460). In addition to diabetes affecting Aboriginal people at higher rates, the frequency of diabetes associated complications - such as proliferative diabetic retinopathy - is also higher among Aboriginal people. An increased risk of cardiovascular disease has also been observed (Szathmary 1994, 460). These findings are in line with recent studies that describe Type 2 diabetes as being most prevalent in minority groups, coupled with increased frequency and severity of diabetes complications within these populations (Harris 1998, C13). The increased burden of NIDDM among minority populations - in general - questions the genetic focus that has been placed on research surrounding causal factors of diabetes for Aboriginal people. Specifically, this relationship refocuses discussion to the impact of poverty as a risk factor for diabetes (Haffner 1998, C3).

In order to shift the lens through which the problem of diabetes in First Nations communities has been approached, this thesis will rely on social science theory to explore both Aboriginal and biomedical understandings of NIDDM. This approach has been described as 'interpretive' in that the emphasis is placed on how people define the world in which they live (Eyles 1988, 2). This approach is focused on grasping the "complexities of context" (Eyles 1988, 2) and it stands in contrast to approaches that seek to construct an objective reality that is decontextualized. An analysis of meaning in context exposes the intersubjective nature of the world. In other words:

“Through theory, science and practice are connected and the apparent objectivity of science is denied.” (Litva and Eyles 1995, 6)

Therefore, contrary to the view espoused by the *Globe and Mail* (Abraham, 1998) article, an understanding of disease can not be achieved through isolating its genetic component parts but rather must be understood as:

“Contingent and historically specific struggles over who provides the definition and makes the diagnosis.” (Litva and Eyles 1995, 11)

In the context of NIDDM, few studies have focused on the lay perceptions and understandings of diabetes in Aboriginal Communities (Boston et al. 1997, 5).

Additionally, little work has been done to establish the sociocultural meanings of the illness. Nonetheless, these meanings have a significant impact on how people approach health and illness - and this thesis will focus on the influence of these perceptions.

A focus on the cultural knowledge surrounding diabetes has largely emerged from a recognition that existing treatment and prevention measures for diabetes have not been successful (Boston et al. 1997, 5). Two books, *Diabetes as a Disease of Civilization* (1995) and *Diabetes in the Canadian Native Population: Biocultural Perspectives* (1994) have articles that deal explicitly with cultural knowledge surrounding diabetes. Boston et al. (1997, 5) have also taken a cultural focus in a study of Cree understandings for diabetes. Underlying this particular study was the belief that any intervention for diabetes prevention had to be aimed towards Cree knowledge and experience of the disease. The study itself identified barriers within health care that included: the potential for miscommunication among clients and health care providers;

and the impact of perceptions of weight on attitudes towards ‘obesity’ as a risk factor for diabetes. The premise for the study was that knowledge of these perceptions would provide tangible directions for future health care directions.

However, within the study by Boston et al.(1997), it was not always evident how perceptions of diabetes could be used to develop health care interventions. Specifically, discussing health and causation often ventures into areas existing beyond a biomedical framework for understanding thus making intervention within a biomedical framework difficult. Within discussions of causality, Cree related diabetes to the decline in bush life associated with “white man” and the socioeconomic changes that have accompanied the James Bay Agreement and the corresponding hydro-electric dam (Boston et al. 1997, 9). When applied to potential health care interventions, knowledge of these perceptions may highlight potential mistrust between health providers and clients. Nonetheless, I would argue, that to end discussion at the level of ‘intervention’ focuses discussion within the confines of a biomedical framework and therefore obscures the possibility for any solutions to exist outside of this perspective. In other words, an opportunity to highlight the social, economic, political and historical dimensions of the environment in which people *become* ill is effectively lost. The lines of enquiry found within social science provide the opportunity to explore these dimensions. The following section will outline the general theoretical backdrop used in this thesis.

Theoretical Framework

Within the thesis an attempt was made to weave theory into each of the chapters in order to highlight the implications of the findings as they were being presented. The arguments made have largely emerged from the post-structuralist tradition – with a particular focus on the writings of Michel Foucault. In general terms, post-structuralism is concerned with: the crisis of representation and the instability of meaning; the absence of a ‘secure’ foundation for knowledge; and the inappropriateness of Enlightenment assumptions that describe a rational and autonomous subject (Boyne 1996, 398). Post-structuralism therefore concentrates on the ways in which individuals are constituted as subjects. In other words, it focuses on the intersubjective connections between individuals and societal structures. Within the context of this thesis, post-structuralism illuminates the relationship between the body and society. That is, this line of enquiry raises critical questions surrounding the concept of ‘expert’ knowledge and highlights the potential impact of this knowledge on health and illness.

Many of the studies that describe perceptions and meanings of diabetes fail to raise these questions, which I would argue limits their ability to highlight the “radical epistemological potential” (DeLauretis 1987, 2) of these meanings. For example, according to the previously mentioned study by Boston et al.(1997, 11):

“Social and cultural barriers persist that *impede the flow of knowledge and understanding of the disease* between the Cree communities and the health care practitioners” (emphasis mine).

The sense that knowledge is 'impeded' in this statement advances the position that a *correct* source of knowledge exists that is blocked through 'social and cultural barriers'. Sensitivity to these barriers does not critically question the concept of 'expert knowledge' in relation to the body. Rather the focus in this study becomes how to 'intervene', or in other words, how to convey this 'knowledge' in a way that breaks through social and cultural barriers. Post-structuralist theory helps to highlight an important possibility that is obscured within this study – specifically, the potential for everyday knowledge to contest and redefine official sources of knowledge. In effect, local understandings of health and illness challenge the concept of a 'universal knowledge' of the body. Implied in the study by Boston et al. (1997) was the perspective that there exists a universal and objective knowledge for the prevention of diabetes. Thus the underlying conclusion, and the foundation for intervention, articulated that this knowledge required translation, rather than transformation.

This concept of a 'universal', and thus objective knowledge is implicit within a biomedical framework. According to Foucault (1990, 59) the process whereby knowledge was normalized was achieved through the ritual of confession. This confessional science emerged through: 1/ The clinical coding of the inducement to speak; 2/ The postulate of causality; 3/ The truth being hidden to the subject; 4/ The need for interpretation – confessor and interpreter; and 5/ The distinction of the normal and the pathological (Foucault 1990, 59). Through these practices there emerges a knowledge of the subject where the subject is ignorant of herself. In contrast to this process of

'normalization', this thesis seeks to approach knowledge of diabetes in terms described by Haraway (1991, 190): particular and specific embodiment rather than a "false vision promising transcendence of all limits and responsibility".

In addition to challenging the concept of a 'universal body', conversations about 'health' also led individuals to connect 'health' with other areas of life (Eyles 1988, 13). Kleinman and Kleinman (1994, 714) have described this process whereby the retelling of illness narratives in China, especially of neurasthenia, authorized social memory and thus represented oblique criticism of the cultural revolution – generally regarded as the source of the illness. Within these narratives bodily memory, biography, and social memory merged in a process where:

"The memory of bodily complaints evoked social complaints which were not so much represented as lived and relived in the body."

This transition between illness being *represented* versus *lived* is significant in revealing that the consequences of the illness experience exist beyond the biological sphere.

Kleinman (1994, 174) noted that:

The expression of their symptoms was a rhetoric of complaint aimed at negotiating improvements in life situations that they perceived as hampered or even ruined by political forces beyond their control (Kleinman 1994, 175).

In a similar vein, this thesis will explore the processes through which individuals negotiate livable and achievable solutions.

Towards this goal, the thesis will juxtapose narratives of the community members with biomedical narratives. This approach will help to contextualize both the

‘objective’ and ‘subjective’ realities of NIDDM - the premise for this argument being that these definitions are in a constant state of flux and negotiation. Part of the rationale for this discussion emerges from a concept of society based on ‘lifeworlds’ and ‘systems’ (Habermas, cited in Love 1995, 57). The lifeworld represents the locus of moral-practical knowledge (relations of meaning) coordinating itself through communicative action - referring to action that is oriented towards both self and mutual understanding. In contrast, the system exists politically and economically. The effect of the system is to increase lifeworld tensions and to frustrate lifeworld potentials (Habermas, cited in Love 1995, 57). These tensions are evident in contesting definitions for health and illness. Conflict results from increasing complexity in the system subverting/displacing the meanings found in direct experience with the lifeworld. In the context of NIDDM, the divergences between the official definitions and community definitions for NIDDM can be considered evidence of such displacement. This suppression of the moral and experiential dimensions of illness by the rational and technical sphere is one example of the “colonization of the lifeworld” (Good 1994, 53).

Within the thesis, a focus on narrative provides the means to explore the experiential knowledge surrounding diabetes. Within a biomedical framework, the narrative of the illness experience is only important to the extent that this narrative is revealing of the physiological state of the individual and can contribute to the clinical narrative (Good 1994, 83). Shifting the lens somewhat, a focus on the ‘embodied’ form of an illness becomes an integral response to the shift in the lifeworld provoked by the

'illness' experience (Kleinman 1988, 9). Becker (1997, 25) has stated that narrative can be considered an analytic tool as it is arguably our primary means of accessing the world of bodily experience. In this context, the role of narrative becomes essential to linking experiences and events with personal meaning. Additionally, narratives serve to highlight the cultural contexts of these accounts. Therefore, narrative of a chronic illness is not simply a story of personal experience – it is also deeply embedded within the institutional structures that influence its production (Saris 1995, 39).

A study of 'experience' as expressed in narrative form questions and explores how concepts of the 'self' are produced. Within many interpretations, the notion of 'experience' is presented as uncontested evidence. Nonetheless, 'experience' in the sense used in this thesis is not entirely subjective. When presented in this light, agency becomes an inherent attribute of individuals and thus decontextualized (Scott 1992, 25). Within this perspective, the hazard exists for experience to be interpreted as evidence for the *fact* of difference rather than an inquiry into how difference is established. According to Scott (1992, 26):

“It is not individuals who have experience, but subjects who are constituted through experience.”

Therefore, in the sense used, 'experience' is not outside of the speaker and thus universal, but is rather historicized. In bridging the individual with the collective, social experience is both shared and fragmented along axes such as gender, race, class. Experience becomes a medium of interaction between the social spaces of institutions and the body self. A focus on *relations of power* provides an account of how subjects and the

possibility of agency are realized (Sawicki 1991, 21; Butler 1992, 39). Within this framework, “no subject is its own point of departure” (Butler 1992, 42); rather it is relations of power that influence “who will be the subject who speaks...and to whom” (Butler 1992, 41). Within this definition of the subject, agency is *structured* but not *forced*. According to Foucault, power is only exercised over “free subjects and only insofar as they are free” (Sawicki 1991, 25). Thus the possibility of agency emerges from a social field characterized by unstable and heterogeneous relations of power. Agency is realized through the fluidity of these relations - although it never stands apart from them.

In sum, this research will focus on the definitions of NIDDM emerging from both the lifeworld and the system – while simultaneously recognizing the potential for both of these categories to be reshaped and changed through negotiations about health. In order to provide a background for this discussion, the following section will outline the specific definitions of health that are utilized by both community members and health care providers. These definitions found the cultural context in which both health care providers and community members make decisions regarding health and illness management. In the context of this thesis, discussing ‘general health’ will help to frame further discussions surrounding diabetes management (Chapter 3), understanding of causal factors (Chapter 4) and resistance (Chapter 5).

General Health

The majority of community members (14 individuals) responded that they consider illness to be “inevitable”. In contrast, health care providers held the perspective that illness is largely preventable. This perspective was evident when health care providers were asked to comment on the overall health of these communities. All of the health care providers stated that they consider these communities to be unhealthy and the majority of these providers attributed this poor health to personal lifestyle choices.

The relationship between individual lifestyle and health became apparent in discussions surrounding diabetes. According to Karen:

“In other places, pop and chips are kind of out. People don’t really do that anymore. We do tend to be behind the times on the island I think. Whether that’s sort of self-inflicted, I don’t know. But I think we need to catch up to what everyone else is doing, as in living healthier lives.”

Related to this discussion of ‘healthier lives’ is the perspective that individuals in the community do not actively pursue health. This perspective becomes evident in Robert’s discussion of the length of time diabetes has been a problem in these communities:

“It’s been a problem for years really. And then you get the diabetes running in families too. You get one or two people and then you start fishing around and then you find that the whole family back to a grandparent, are all diabetic, and didn’t do anything about it mostly.”

Within this statement there is a sense that individuals do not act in ways that can prevent illness. Additionally, there was a focus among health care providers on health as a physical condition. This perspective was evident - where 16 of the respondents discussed obesity as directly contributing to poor health.

In contrast, the majority of community members (18 individuals) expressed holistic definitions for health. Holistic was often used to describe a balance between physical, mental, emotional, and spiritual health. Doris stated:

“In light of what I said, to me I think health is being comfortable where I am.”

David, discussed the necessary components to achieving a healthy state:

“You have to have a healthy mind, body, and spirit. People have maybe a healthy body, but their mind is all messed up. Spirit and emotions are all screwed up. Maybe their spirituality is missing and their mind starts going and emotions start going, and their body goes last. When your spiritually isn't balanced, your body starts going too. Once something is off, everything else just sort of falls off too”.

Included in this holistic framework, many individuals, such as Dorothy, discussed the importance of culture to achieving a state of health:

“And I think when you learn more about your culture, any culture, not just having to be Ojibway, you learn more about your tradition and I just think it heightens your whole, I don't know, your self esteem, your proudness, and your health is just going to benefit. Like it's just this ripple effect. It's hitting all these positives throughout.”

Margaret re-iterated this perspective:

“Culture and language, that also is part of your health. Because if you don't have those, you're not healthy in that sense.”

Within the holistic definitions for health put forth by community members, health involves more than sickness care and includes a place for 'culture'. These community narratives resonate with the recommendations of the Royal Commission on Aboriginal Peoples (RCAP, 1996) where it was emphasized that although traditional norms and values change, they retain a powerful influence over health. The focus of

health care providers on the physical impact of poor lifestyle choices - such as obesity - provides a dramatically different framework to approach health. Illness, according to the health care providers, is based on individual lifestyle choices and is therefore largely preventable.

The framework for health that has been used by the health care system often does not relate to Aboriginal definitions for health and has therefore been described as inadequate. According to the RCAP (1996) these inadequacies are politically significant as:

"It must be clearly understood that, when dealing with First Nations People, whether it be in education or with health, it must be in the context of the culture, whatever that culture may be, or it is just another form of assimilation" (RCAP, 1996).

Culture becomes a site where health is experienced and understood, linked to societal structures and evolving through individual and social action (Dyck, 1992). The point to be made here is that how individuals pursue health is *contingent* on these definitions. In other words, the 'action' taken surrounding health will be informed by cultural definitions for health. In the context of this study, these definitions emerge in narratives about diabetes prevention, treatment, and causality. The following section will outline the framework used in this thesis to approach diabetes in the "context of culture".

Thesis Outline

Chapter Two focuses on research methodology. Specifically, this chapter includes: an outline of research goals; a description of the interview process and the

structure of the interviews; and the process through which data was analysed. Limitations in the study sample are also outlined.

Chapter Three embarks on a discussion of diabetes care - specifically, diagnosis and treatment. In other words, this chapter explores biomedical 'actions' surrounding diabetes and the impact of these actions in the lifeworld. This action, in the form of diabetes management, is based on controlling the blood sugar level through measurement. This quantitative diagnosis obscures the uncertainties underlying biomedical practices – and thus a central component of this chapter will be to outline the uncertainties underlying the rationale for 'intensive' management of NIDDM. Central to this argument is that biomedical actions surrounding diabetes are not without consequence. These consequences become particularly significant when health is conceived beyond a biomedical framework.

Chapter Four explores Aboriginal and biomedical perceptions of cause, and thus this chapter defines the 'problem' of diabetes. Underlying definitions of cause are two divergent courses of action surrounding diabetes – each of which has underlying moral implications. Biomedical narratives suggest that diabetes is related to an individual's lack of control over lifestyle choices whereas community narratives suggest that factors outside of an individual's control, such as genetics, are causing diabetes. Thus underlying these divergent perceptions of cause is the *definition* of the problem of diabetes as either an individual or a collective phenomenon. Importantly, perceptions of cause are related to potential solutions. Within a biomedical framework solutions are

focused towards improving individual behaviour. In contrast, community members described solutions based on a collective return to culturally based knowledge and identity.

Chapter Five focuses on the divergent definitions of the ‘body’ emerging from biomedical discourse and the community narratives. Within this chapter these definitions for the body will be discussed in terms of ‘resistance’. The chapter is divided into two sections. The first explores how community narratives surrounding causal factors outline a universal and genetically distinct ‘Native’ body. The second section explores perceptions of ‘healthy bodies’ – specifically the relationship between body size and health. In the context of diabetes, this discussion is particularly relevant due to the emphasis placed on obesity as a risk factor. It will be argued that the competing definitions of the ‘body’ that emerge from community narratives and biomedical narratives form a foundation from which to discuss ‘resistance’.

Chapter Six will revisit the key findings and will outline certain theoretical implications of the research.

Chapter 2: Methodology

This study used qualitative research methods, implying an inductive approach to research. In this framework, induction is used to interpret or reconstruct reality in order to understand the processes through which people ascribe meaning to their lives (Elliott and Baxter 1994, 137). The premise for this approach is that actions surrounding health and illness are based on these meanings. As was previously mentioned, the majority of research relating to the occurrence of NIDDM among First Nations People has had a quantitative focus - such as, studies to establish incidence and prevalence rates. This study can be considered a corollary to the quantitative studies that have already identified the ‘problem’ of NIDDM in First Nations Communities in terms of numbers. That is, the premise of this study is the possibility for explanation to be enhanced by “being able to tell the statistics *and* the stories” (Elliott and Baxter 1994, 136).

This research initially involved identifying the research topic, establishing the method of data collection, and identifying a sample population. Each of these steps was performed in collaboration with the Health Director and the United Chiefs and Councils of Manitoulin Mnaamodzawin Health Board (UCCM Health Board) in order to ensure that the research goals fit with the specific needs of these communities. The details of this process will be elaborated further in the following section.

Development of Research Goals

A research proposal was written in December, 1997 in which I outlined an interest in studying the symptoms, causes, cures, and consequences of NIDDM within First Nations in Canada. Professor Wayne Warry approached Marlene Nose, the health director for United Chiefs and Council of Manitoulin Health Services, with the research proposal in January, 1998. Marlene Nose then discussed the research proposal with the United Chiefs and Council Mnaamodzawin Health Board (UCCM Health Board). The health board had previously identified diabetes as an important health problem facing each of the five First Nations' communities represented by this board and an interest in the proposed research was expressed.

An initial meeting with Marlene Nose took place in Sudbury on April 16, 1998. At this meeting the research proposal was discussed. It was suggested that the emphasis be placed on *perceptions* of diabetes rather than specific *knowledge* about the disease. The sense given during this meeting was that knowledge of diabetes was quite high and that, rather, other issues were getting in the way of diabetes treatment and prevention. It was also established that the study would be based on a series of unstructured interviews with both clients and health care providers. Clients would include individuals both with and without diabetes in order to explore any differences in perception between these two groups. Additionally, the health board articulated that they would like the study to take place in two communities. Information in two communities would be more beneficial for the health board as it would provide access to a wider range

of perceptions and give some indication about what perceptions could be generalized between different communities. It is important to mention, however, that due to the small sample size this study should be considered *exploratory*. In other words, the sample size is too small to provide substantial information in the thesis regarding potential differences between the two communities. Remaining undecided at the time of this meeting was whether group or individual interviews would be used.

Approval by the UCCM Health Board was required before this research could take place. Following this initial meeting the research proposal was modified and a check-list of relevant themes for interviews with both clients and health care providers was developed (see Appendix 1). Each of these items was presented to the UCCM Health Board at the beginning of May, 1998. At this meeting the research proposal was approved and the community of Whitefish River was chosen as one location for the research. Additionally, it was decided that a community report would be submitted to the health board, in addition to the Masters thesis, in order to provide a document that would be beneficial for future health care planning. It was established that this report would be submitted before the completed thesis (see Appendix 2).

At this point in the process, I had approached the community of West Bay as a second potential research location. West Bay has its own autonomous health committee and approval for research in this community was required by both the health committee and Chief and Council. The proposal was to be presented at the June 11, 1998 Chief and Council meeting. Nonetheless, it was not tabled at that meeting. The

following Chief and Council meeting was not for several weeks and therefore I decided to remove the research proposal from West Bay due to time constraints. Following a discussion with Marlene Nose on June 12, it was decided that the research would also include the community of Sucker Creek. That afternoon, Marlene Nose and I met with Shirley Corbiere, the community health representative (CHR) for Sucker Creek following which the research was approved for this community.

The Interview Process

The Community Health Representatives for both Whitefish River and Sucker Creek were provided with a letter to distribute to potential participants. This letter outlined the purpose of the research, the structure and length of time of the interview, and an invitation to contact the community health centre if they were interested in participating (see Appendix 3). Additional calls were made by both CHRs in order to schedule interviews and request participation from individuals who had not yet responded to the letter. The goal was to conduct interviews with a total of 20 individuals from Whitefish River and 10 individuals from Sucker Creek – equally divided between individuals with and without diabetes. Both CHRs were requested to consider a sample of participants that would consist of both males and females from a variety of age groups. Interviews took place at both the community health centres or at participant's homes. Each interview was approximately one hour long.

Additionally, interviews with both Native and non-Native health care providers took place. A letter was sent to physicians at both the Mindemoya and Little Current Hospitals to request their participation in the study (see Appendix 4). Health care providers interviewed included doctors, nurse practitioners, nurses, community health representatives, traditional healers, mental health workers, and dieticians. A focus group took place with the doctors at the Mindemoya hospital. The breakdown of these interviews was as follows:

A/ Total Community members interviewed:	28
<i>Individuals with Diabetes Interviewed:</i>	15
• <i>Sucker Creek:</i>	5 (3 male:2 female)
• <i>Whitefish River:</i>	10 (5 male:5 female)
<i>Individuals without Diabetes Interviewed:</i>	13
• <i>Sucker Creek:</i>	5 (0 male:5 female)
• <i>Whitefish River:</i>	8 (1 male:7 female)
B/ Total Health Care Workers Interviewed:	18

Interviews addressed a range of themes in order to explore general perceptions. These themes included the following general categories: general health; causes of diabetes; conditions surrounding diagnosis; treatment; diabetes management; knowledge of diabetes; consequences of living with diabetes; and future recommendations for health care planning. Additionally, time was spent observing traditional diabetes education workshops and informal discussions surrounding diabetes often took place while waiting for participants at the community health centre.

Interviews occurred in a two month period, from early May 1998 until the middle of July

1998 and were transcribed from July until mid September. Following transcription, analysis of the data occurred from September until the end of November 1998. All names have been changed in this report to preserve anonymity. Please see Appendix 5 for details about individual participants. The following section will outline the structure of the interviews.

Structure of the Interviews

The interview has been described by Eyles (1988, 7) as the method that ‘lies between’ the survey and participant observation. In a formal interview, questions are asked and answers recorded in a standardized form. In contrast, informal interviews are based on the interaction between the researcher and the respondent (Eyles 1988, 7). Within this format, conversation is used in order to ensure that questions have the same meaning for all respondents. Although the wording and sequence of the questions are not explicitly defined, there is a framework – in the form of a check list – to ensure that key issues are discussed.

This study used an informal interview format. According to Bernard (1995, 209) these unstructured interviews are not informal in the sense that they are based in a ‘clear plan’. Nonetheless, they are characterized by a minimum of control on the part of the researcher, allowing people to express themselves in their own terms. The role of the researcher within this format is to focus conversation on a particular topic whilst permitting the informant to define the content of the discussion (Bernard 1995, 211).

This type of interview format is therefore useful for sensitive issues as it attempts to set the respondent at ease.

A focus group was also used in this study to establish the perceptions of NIDDM on the part of physicians. Focus groups are best suited to studies of attitudes and cognitions (Morgan 1988, 17) and are particularly useful for exploring participants' experiences and perspectives (Morgan 1988, 25) – a central goal of this research. One advantage of focus groups is the opportunity to observe and record a high amount of interaction on a topic in a limited period of time (Morgan 1988, 15). Due to time constraints, there were practical difficulties in establishing individual interviews with physicians and therefore the focus group was a suitable option.

Each of the interviews and the focus group were taped, with only a few exceptions – the premise being that data collection based on individuals own descriptions would result in a more accurate analysis. Additionally, field notes were taken during the entire research process. These notes helped to cross check potential biases along with outlining my own attitudes at the time of the interview. The field notes also included observations gained through time spent at the community health centres as well as the interactions of members of a planning committee for a diabetes awareness day. Field notes were therefore beneficial to recording methods, providing descriptions that helped to establish context, and in recording early analytic notes. These notes formed the basis for an initial report to the community in July (see Appendix 6). The following section

will outline the details of the analysis that followed the field work component of the research.

Analysis

Analysis of the data involved coding the transcribed interviews into relevant themes and topics. Following this process key codes were identified. Within this study, data was coded line by line – allowing the development of precise coding categories. In this sense, the study used ‘inductive code development’ – referring to the process whereby the code development occurs while concomitantly reading through the data (Wakefield 1998, 117). The use of analytic induction helps to avoid prior categorization of the data and identifies earlier categories that may not fit with the data (Eyles 1988, 4). The process of progressive categorization and refinement of theory is based on the premise that the emergent findings will be consistent with the data. Theory within this framework is not conceived in terms of logical deductions but rather through relations between observed phenomena (Eyles 1988, 4).

The selection of codes was based on a number of criteria. Firstly, codes were developed based on topics previously identified for the interview checklist. This checklist included broad categories such as, ‘cause’, ‘general health’, and ‘diabetes treatment’. Within these general categories, specific topics were identified based on the transcribed text of the interviews. Therefore, the mention of specific topics throughout the interview sample were categorized and key themes were established. Additionally, ‘counter-

stories' were included that did not fit with previously established categories. Ideally, the importance of different themes to different groups within the sample (i.e. sociodemographic characteristics) could be established. Nonetheless, this would require a larger sample size than was possible with this study. After identifying key coding categories, the relative importance attributed to these categories was established.

A computer based qualitative research analysis program, called NUD.IST, was used to assist the analysis. NUD.IST stands for Non-Numerical Unstructured Data – Indexing, Searching, and Theorizing. Computer assisted data analysis has a number of advantages including: flexible data management where theory can be developed in relation to the data; increased retrieval capacity; and a flexible indexing system (Wakefield 1998, 119). Within NUD.IST themes are coded and then organized into a hierarchical coding system. As was previously mentioned, data was included in text form and sentences were used as the unit of coding. Although it is possible to search through text for keywords or phrases and code based on these retrievals this approach was not used – due to the potential for these phrases to be analysed out of context. This approach to coding creates the potential for the coding scheme to be untrustworthy or unrepresentative (Wakefield 1998, 120). After a general coding scheme was established, codes were moved to different locations or deleted in order to organize the data for further analysis.

The use of this program facilitated the identification of themes for analysis and, given time constraints, it also diminished the amount of time spent sorting data

manually thus increasing the relative time spent analysing. Nonetheless, it is important to mention that NUD.IST is a tool that *assists* analysis – the development of themes and categories for coding is done exclusively by the researcher. Its ability to assist the researcher is based on a number of features. Firstly, NUD.IST will identify the number of documents in which a particular code appears. Secondly, it will identify the proportion of specific documents that are coded for a particular theme. Each of these mechanisms helps the researcher to assess the relative importance of themes. Additionally, it allows the universality or differentiation of key codes to be examined (Wakefield 1998, 122). Code search functions within the NUD.IST program also assist in identifying linkages between themes.

Overall, NUD.IST was beneficial to the analysis. The use of the memo system within NUD.IST facilitated the process of inductive reasoning, through the recording of concepts, particular problems, queries and solutions – thus facilitating theory development in the midst of a large volume of text. A possible disadvantage was the hierarchical ordering of the coding system which perhaps constrained the ability of the researcher to identify certain linkages between coding categories.

Limitations

Although all possible steps were taken to ensure a variable sample, certain biases are apparent in the composition of the interview sample. One potential bias is that more female participants were interviewed than male participants. This result may be

due all interviews being scheduled during the day – creating greater access to individuals who did not work. This result may also be due to less inclination on the part of male community members to discuss illness. Similarly, studies by both Crawford (1984) and Cornwell (1984) had trouble accessing men in order to discuss perceptions of health (cited in Stacey 1988, 148). Many of the interviews with male participants indicated a level of denial surrounding the disease – which may have influenced potential respondents. Therefore, no distinctions can be made between male and female perceptions of diabetes. Additionally, the sample size is not large enough to establish whether different perceptions of diabetes exist within different age categories. My own position as a non-Native researcher may also have affected actual responses within the interviews.

As was previously mentioned, the research took place in two communities: Whitefish River and Sucker Creek. The advantage of having research in two communities was that any perceptions that were specific to either community could be identified. Additionally, it provided the UCCM Health Board with perceptions in two of their five communities and thus contributed to a more a general background from which to approach health care planning for these five communities. Nonetheless, as the majority of the interviews took place in Whitefish River, the thesis can be considered as more representative of this population. Certain differences in perceptions did emerge in the interviews in Sucker Creek. For example, several individuals in Sucker Creek mentioned knowledge of ‘cures’ for diabetes. In contrast, not one individual in Whitefish

River mentioned the existence of cures. Nonetheless, due to the small sample size (10) it was not possible to distinguish whether these differences were important. These differences are therefore not specifically identified within the text of the thesis.

Within the thesis, distinctions are not made between Native and non-Native health care providers. On one level this can be considered problematic as it assumes that cultural groups do not influence the system in which they are working. In other words it assumes that biomedicine is impervious to change through pressures exerted by cultural groups working as health care providers within the system. Indeed, a central premise of this thesis is that these groups *do* influence biomedicine thus questioning the ‘objective’ foundation upon which biomedicine rests. Nonetheless, differences between Native and non-Native health care providers did not appear to be important within the context of this study. This lack of differentiation may, in large part, be due to the small sample size. Additionally, due to the small number of health care providers within the UCCM communities, distinguishing between Native and non-Native health care providers may have compromised individual anonymity within the study. Nonetheless, it is recognized that differences may exist between the perceptions of Native and non-Native health care providers.

Presentation of Results

According to Eyles (1988, 6): “Reality is reconstructed. It is not simply there.” Accordingly the results of this study have been organized in two formats to best

convey this reconstruction. The first presentation of the results is in the form of a report to the USSM Health Board and the community health centres. This report was presented to the Health Board on Manitoulin Island on February 18th, 1999 and individuals at the meeting were given an opportunity to respond to the findings. The purpose of this report was to both outline and relate the findings of this research to future health care planning through general recommendations (see Appendix 2). The second presentation of the results is in the form of the thesis which follows.

Chapter 3: Managing Risk and Uncertainty about Diabetes

*“I wanted badly that truth be a single thing;
Now I know it won't be measured.
It wasn't Heisenberg or Hindemith, but you
Who convinced me
That nothing can be unraveled to its core,
That truth is a field, a cage, a cloud of sound” (Michaels 1997, 65).*

The theme of this chapter is uncertainty, and as such it represents an introspective journey on the part of the reader into what is meant by the notion of truth. The above statement illuminates the disappointment that follows the discovery that truth is not a ‘single thing’ but rather a concept lacking precise description or exact measurement. What is most interesting about this passage is that this discovery is inspired not by the writings of physicists, but rather through an intimate experience with another individual. Embarking on a discussion of uncertainty is particularly significant in the realm of health where “truth” is negotiated in the complex engagements between clinical science and the lifeworld. This chapter will explore how these negotiations translate clinical uncertainty into a certain need for action in the lifeworld surrounding diabetes diagnosis and management.

Medicine has become the “new repository of truth” (Zola 1972, 487) and occupies a central role in defining what it means to be ‘healthy’ or ‘ill’ in our society. As an institution it operates on the premise that it is neutral and objective despite the morally loaded claims at its foundation: that the determinants of health and illness are biological;

that medicine must be scientific; and that scientific medicine is the only way to mediate between people and disease (Doyal, 1988). The process through which society has become increasingly 'medicalized' has been an undramatic, yet insidious phenomenon that has concomitantly embraced and enforced a reliance on 'experts' as the authoritative interpreters of this reality.

Riessman (1983, 4) describes the process of medicalization as occurring in two phases: the medical definition of certain behaviours and conditions; and the use of medical practice as a vehicle for controlling problematic experiences that are defined as deviant. Foucault (1980, 168) argues that at the end of the 18th century, an emphasis on the collective social body construed 'disease' as a problem to be resolved through social policy. Rather than conceptualizing the social body as representative of a 'universal will' Foucault argued that the social body was best understood as the product of material power acting on individual bodies. This power separated bodies into 'normal' and 'abnormal', and explicitly defined the deviant body. This deviancy results in the individual who is ill separating themselves apart, both literally and metaphorically, from society (Litva and Eyles 1994, 1084). This 'deviancy' is due to the underlying belief that illness is a result of individual behaviours (Refer to Conrad, 1980). This new conceptualization of health justified the surveillance of the individual body and the disciplinary activity of medicine was directed towards normalization and social control.

The discussion to follow will focus on biomedical practices surrounding diabetes care. The chapter is divided into two sections. The first will explore the process

of diagnosis of diabetes. The second will explore the treatment regimens resulting from membership in this category. The theme tying these two processes together is that both diagnosis and management of diabetes depend on inclusion into categories of 'risk'. In general terms, 'risk' refers to the probability that a particular adverse event occurs during a stated period of time (Royal Society 1992, 2). Practices surrounding diagnosis focus on a population described 'at risk' for diabetes, referring to First Nation's People. Similarly, practices surrounding management of diabetes focus on a population 'at risk' for secondary complications, referring to individuals with diabetes. As the following discussion will outline, it is through the quantitative assessment of risk that scientific uncertainty is translated into definitive therapy.

Diagnosing Risk

The focus of this section will be to analyze the concept of risk in order to ascertain the material effects of this abstract concept. Approaching disease through the concept of risk has been described as a modern phenomenon (see Beck 1992). Implicit to this concept is the belief that causality follows deterministic laws (Kavanagh and Broom 1998, 437). Castel (1991, 281) describes the societal transformation whereby the notion of danger was supplanted by the notion of risk. As such, risk is treated as an inherent quality of the subject – based on a combination of abstract factors – that render a generalizable event more or less probable for that subject. Through these risk factors, individuals are subject to examination to determine the *real* presence of danger, based on this *abstract* notion of risk. The implications of notions of risk become apparent when

applied to health care policies that are focused on prevention. Within this framework, intervention no longer depends on the presence of an illness but rather an individual's risk of developing an illness. As will be evident in this chapter, it is no longer necessary to manifest explicit symptoms to be diagnosed with diabetes. In this sense it is enough to "construct the objective conditions of emergence of danger, so as then to deduce from them new modalities of intervention" (Castel 1991, 288). This shift from dangerousness to risk effectively multiplies the possibility for intervention with little or no consideration of the human and social costs of these interventions.

The use of the diagnostic test, where screening allows a disease to be identified before symptoms appear, is an example of one such intervention (Lupton 1995, 78). In this sense, the event of the test creates a sense of 'doing something' in the face of the potential for disorder caused by illness. 'Knowledge' of the disease thus emerges as the sword by which the individual will protect herself from the potential threat of disease. Nonetheless, this knowledge is often imperfect and the benefits of screening for the individual – beyond the sense of simply 'doing something' - are not always obvious. In the case of NIDDM, a disease that is often asymptomatic, Rosser and Shafir (1998, 149) argue that there have been no studies that demonstrate benefits, such as the prevention of secondary complications, from early detection. When the concept of screening is expanded to the level of the social, rather than the individual body, its implications become more apparent. In other words, screening can be considered a form of

surveillance resulting in docility of the individual body and the normalization of the social body.

It became apparent in this study that among the individuals diagnosed with diabetes, these diagnoses were often a result of these individuals being at the doctor or at the hospital for reasons other than the traditional symptoms of diabetes (i.e. thirst, excessive urination, fatigue). Among those diagnosed with diabetes, 3 individuals explicitly identified having symptoms pre-diagnosis whereas a total of 10 individuals explained that they were at the doctor for other reasons and were shocked about being told that they had diabetes. In this sense, people without symptoms are required to contemplate the reality of a disease that seems 'hidden' (Lupton 1995, 94) – defined by the 'objective' measurement of the blood sugar level. According to Raymond:

“They tested me about five years ago. I didn't really expect that you know. When I was in the hospital for another reason they did the blood work.”

When asked whether she noticed symptoms pre-diagnosis, Margaret responded:

“No. I wasn't ever thirsty. Or I didn't run to the bathroom. I didn't have none of those. And like I say, they might have been there, but I was busy working and didn't have time to.”

Dennis had a similar perspective:

“When I had that asthma. I used to get pneumonia all the time when I had that asthma. That's when they found out that I had sugar diabetes.”

Interviewer: “Did you have any symptoms or anything before that?”

Dennis: “No.”

Gregory, from Sucker Creek, described his reaction to the diagnosis:

“Yea. And the thing is when I did find out, it was just by chance too that I found out, ... It was a surprise really.”

Additionally, nine of the health care professionals mentioned situations where individuals were seeking health care for reasons other than diabetes. According to Beth:

“I find a lot of people are diagnosed as diabetic is on like an emergency type basis. They go in maybe for something else and the doctor, through blood work, finds out, hey you’re a diabetic. Or they’ve had something happen to them and it’s because of diabetes and they didn’t know they had it.”

With specific reference to symptoms, John stated that:

“Probably about a third of the diagnosis are based on symptoms, and those are based on fatigue. Compared to people with the classical symptoms of diabetes, weight gain weight loss. Two thirds are being diagnosed in routine physicals.”

Thus, in the majority of cases, client experience of symptoms is not the most important dimension of diagnosis. Rather, it is the objective measurement of the blood glucose level that determines membership in the universal category of ‘diabetic’.

Emke (1993, 60) argues that medical control of the body has been assisted by increasingly complex surveillance technology. These technologies are directed towards a quantifiable knowledge of the disease through an emphasis on accurate measurement. In this framework, risk is evaluated numerically and thus the measurement of the blood sugar level represents a concrete definition of danger. Through the presentation of this concrete number, all other scientific uncertainties – including factors that may modify this risk – disappear.

Yet the objectivity behind diagnosis can be questioned. Harrison's *Principles of Internal Medicine* (1991, 1739) describes this process:

“The diagnosis of symptomatic diabetes is not difficult. When a patient presents with signs and symptoms attributable to an osmotic diuresis and is found to have hyperglycemia, essentially all physicians agree that diabetes is present. There is likewise little disagreement about an asymptomatic patient with persistently elevated plasma glucose concentrations. The problem arises with the asymptomatic patient who for one reason or another is considered to be a potential diabetic but has a normal fasting glucose concentration in plasma.”

In this sense, despite efforts to ensure objectivity – reflected in the blood sugar level – the path to diagnosis for certain individuals remains uncertain. Nonetheless, clinical guidelines have been established clearly defining diagnostic criteria.⁴ As such, this diagnosis represents an “epidemic of signification” (Treichler, 1987) whereby the individual subject, regardless of the existence of symptoms, becomes implicated in a wide-range of interventions. The concept of ‘risk’ moves from the abstract to the intimate (Lupton 1995, 84)– becoming a reflection of the individual’s ability to manage the ‘self’. For diabetes, the underlying belief is that early detection of this insidious disease will prevent further disease – that is, the associated secondary complications. The diabetic individual is now at risk for further disease, and is required to participate in activities to minimize this risk. The next section will consider the clinical construction of diabetes where the scientific basis for management has led to considerable debate in the scientific

⁴ Currently, there has been a lowering of the diagnostic criteria for fasting plasma glucose (FPG) level (from >8.0 mmol/l to >7.0 mmol/l) following the application of the revised American Diabetes Association criteria for the diagnosis of diabetes (see Expert 1997, 1183). The implication of this change being that the incidence of diabetes will increase.

community as to what action to take. The consequences of this construction on the lifeworld will then be explored in the community narratives surrounding diabetes management.

Clinical Construction

The publication of the results of the Diabetes Control and Complications Trial (DCCT) provided clear evidence to show that strict glycemic control prevents the progression of diabetic retinopathy, nephropathy, and neuropathy in patients with insulin-dependent diabetes mellitus (IDDM) (DCCT 1993, 977). The similarity between the microvascular complications observed for both IDDM and NIDDM has led to the prediction that the maintenance of near-normal glycemic levels in patients with NIDDM will also help prevent these complications (Clark and Vinicor 1996, 86). This phenomenon, referred to as the “glucose hypothesis”, predicts that there is a correlation between abnormal glycemic levels and the occurrence of complications. Nonetheless, differences between the pathophysiology of IDDM and NIDDM coupled with a lack of evidence supporting intensive management of NIDDM has created a situation of considerable uncertainty surrounding proposed treatment guidelines. The results of the DCCT have increased debate over potential implications for the treatment of NIDDM (Clark and Vinicor 1996, 81; Nathan 1995a, 251). This debate acquires increased importance when considering that of the two forms of diabetes, NIDDM is far more common, accounting for 80% to 90% of diagnoses (Savage 1996, 97). The following section will explore differences in pathophysiology between NIDDM and IDDM.

Pathophysiology of IDDM and NIDDM

Diabetes mellitus is a disease of metabolic dysregulation - primarily the dysregulation of glucose metabolism - and is accompanied by both long-term vascular and neurological complications (Nathan 1995b, 1). The normal process of glucose homeostasis involves insulin secretion; glucose uptake by the liver, gut, and peripheral tissues; and the suppression of glucose production in the liver (DeFronzo 1992, 318). Although the use of insulin dramatically reduces mortality for IDDM, individuals who are treated with insulin develop seemingly unavoidable secondary complications, including blindness, kidney failure, and peripheral and cardiovascular disease (Nathan 1995b, 1).

Many of the early observations about diabetes focussed on insulin-dependent diabetes mellitus (IDDM). Until relatively recently, IDDM was not distinguished from non-insulin dependent diabetes mellitus (NIDDM) the second major clinical expression of this disease. Individuals with IDDM have an absolute insulin deficiency which is accompanied by an atrophy of the islets of the pancreas (Nathan 1995b, 5). In contrast, individuals with NIDDM have a nearly normal islet mass, but do not produce sufficient insulin to meet the increased insulin demands that result from insulin resistance. Additional distinctions between IDDM and NIDDM are observable in the age of onset. IDDM is generally a disease of childhood, most cases appearing individuals younger than 20 years, whereas NIDDM mainly occurs in patients older than 40 years.

Insulin Resistance

The observation of increased glucose levels with normal or high absolute insulin levels led to the suggestion that 'insulin resistance' may be a causative factor in the onset of NIDDM (DeFronzo 1992, 324). Insulin activity refers to the binding of insulin to cell-surface insulin receptors. For insulin resistant individuals, a decrease in insulin receptors has been found. Nonetheless, no abnormalities are apparent in the structure of the insulin receptor or in the compound integral to its functioning, tyrosine kinase (DeFronzo 1992,324). However, individuals with NIDDM do show impaired insulin-mediated stimulation of tyrosine kinase and autophosphorylation (Nathan 1995b, 5). A corollary of insulin resistance is the decreased muscle uptake of glucose. Whether there are abnormalities in the glucose transporter responsible for glucose transport in muscle remains undetermined.

The occurrence of insulin resistance, however, is not sufficient to explain the glucose intolerance that results in NIDDM (Moller and Flier 1991, 938). Additionally, many insulin resistant individuals do not develop diabetes (Nathan 1995b, 5). These individuals are able to increase insulin secretion to a level where insulin resistance is overcome. Therefore, individuals who do develop NIDDM decompensate; implying that they are unable to increase insulin secretion past a certain level. As a result, a decrease in insulin secretion is observed in the transition to NIDDM (Moller and Flier 1991, 944). As indicated in the literature, uncertainty exists concerning the biological pathways that lead to NIDDM.

Debates Surrounding Treatment

Foremost in the debates surrounding the use of intensive treatment for NIDDM is the lack of long-term studies examining the risks and benefits of these therapies for patients with NIDDM (Turner 1998, C35; Nathan 1995a, 251; Clark and Vinicor 1996, 86). The scientific uncertainty surrounding potential risks and benefits is evident in the following statement:

“The doctrine of glycemic near-normalization for care of NIDDM – although remaining central to the diabetologist’s credo – is still regarded as a strongly held belief rather than knowledge-based fact. However strongly the findings of the DCCT and the growing epidemiologic data to support this thesis, direct, scientifically acceptable evidence of benefit of glycemic near-normalization in NIDDM is still awaited.” (Berger et al. 1996, 157)

In Germany, this lack of evidence prompted a non-drug treatment strategy based on nutritional recommendations and increased physical activity (Berger et al. 1996, 153). Despite problems associated with motivating lifestyle changes, the authors maintain that this is the only possible strategy based on “sound pathophysiologic grounds” (Berger et al. 1996, 153).

Nonetheless, in the literature, a hesitancy towards ‘aggressive management’ of NIDDM is the exception rather than the rule. The recommendations of a forum reviewing issues regarding intensive management of NIDDM advocated the following (Henry and Genuth 1996, 175): 1/ Near-normal glycemia levels as the goal of treatment; 2/ Glycemic targets adjusted according to clinical factors such as advanced age; 3/ Comprehensive and repetitive instruction about diet, exercise, and the use of blood

glucose self-monitoring; 4/ Early institution of intensive management of hyperglycemia, initially emphasizing diet and exercise therapy; progressing to oral hypoglycemic agents and finally to insulin therapy; 5/ Aggressive attempts to reduce cardiovascular risk factors, nephropathy and neuropathy; 6/ The use of a 'team approach' in therapy, using a physician, diabetes educator, nurse, dietician and other health care professionals. Thus, uncertainty in clinical science is translated into clearly defined therapeutic goals – embracing an approach that has as its goal near-normal glycemia levels (implying intensive management).

The uncertainty over the scientific basis for applying the glucose hypothesis to NIDDM originates from a number of observations, particularly the existence of adverse side effects. The DCCT cited increased incidence of hypoglycemia and weight gain as potentially adverse side effects of intensive insulin therapy (DCCT 1993, 977). These increases are a concern for patients with NIDDM where large doses of insulin may be required to overcome insulin resistance (Henry 1996, 97). Additional concerns regarding intensive treatment relate to the potential for the treatment to cause or contribute to cardiovascular disease (Turner 1998, C35; Nathan 1995a, 254). It has been suggested that exogenous insulin may contribute to atheroma (Stout 1990, 631), and epidemiologic studies show a relation between high plasma insulin concentrations and myocardial infarctions (Desprès et al. 1996, 952). Studies in the UK have shown that 9% of patients with NIDDM develop microvascular complications within 9 years of diagnosis, whilst 20% have macrovascular complications (Turner et al. 1996, 136).

Additionally, macrovascular disease accounts for 59% of the mortalities of these patients. The profound consequences of even a slight increase in cardiovascular disease in patients with NIDDM has led some researchers to suggest that the increased risk of macrovascular complications associated with intensive therapy outweigh its potential benefits (Nathan 1995a, 254).

The recent publication of the United Kingdom Prospective Diabetes Study (UKPDS) sheds some light on these issues (1998, 837). The UKPDS demonstrated that intensive glucose-control treatment substantially reduces the frequency of microvascular complications in individuals with NIDDM but has no effect on diabetes-related mortality or myocardial infarction. The study outlines weight gain and the risk of hypoglycemia as disadvantages. There was no evidence that intensive management had an adverse effect on macrovascular disease. Nonetheless, in the University Group Diabetes Program there was no evidence that improved glucose control, by any therapy, reduced the risk of cardiovascular complications (UGDP 1978, 37). This study did, however, show an increased risk of cardiovascular mortality in patients given sulphonylurea.

Although, the UKPDS study clarifies certain issues; specifically, the benefits of intensive therapy on microvascular complications; there remains significant uncertainty concerning the usefulness of intensive therapy for patients with NIDDM. The significance of macrovascular complications for NIDDM related mortality coupled with the finding that glucose control has no effect on macrovascular complications (UKPDS 1998, 837), creates a level of uncertainty surrounding the aggressive management of

NIDDM. Currently, the effects of glucose control on different groups of people with NIDDM, such as the elderly, remains unknown (Colwell and Clark 1996, 178).

Additionally, it is unknown whether there should be different goals for glucose control at different stages of the disease.

The Uncertainty Principle

“In the precise formulation of the law of causality, ‘If we accurately know the present, then we can calculate the future,’ it is not the second clause that is wrong, but the first one. We cannot, as a matter of principle, gain knowledge of the present in all its determinants...the invalidity of the law of causality is definitively established by quantum mechanics.” Werner Heisenberg

The above statement reads more like an introduction to postmodernism than what one would perceive emerging from one of the founders of quantum theory.

Nonetheless, Heisenberg’s ‘Uncertainty Principle’, postulating that if you measure position accurately you must sacrifice an accurate knowledge of momentum, is a telling assertion of the uncertainties underlying even the most ‘pure’ of sciences. Clinical science demonstrates that the knowledge forming the rationale for management of NIDDM is also affected by a level of uncertainty. Nonetheless, this knowledge and the power it expresses surrounding diabetes management does not repress, but rather incites action. For individuals who are faced with the occurrence of diabetes and a potential loss of ‘health’ (in the form of complications) the possibility ‘not to act’ is excluded. What makes the power articulated over diabetes management acceptable is that:

“It doesn’t only weigh on us as a force that says no, but it traverses and produces things, it induces pleasure, forms knowledge, produces discourse.” (Foucault 1980, 119)

What remains unspecified in this discourse is that individuals are morally bound to assume responsibility for their health. In the case of diabetes, responsibility is expressed through careful management of the disease.

The need for the individual to assume responsibility for their illness is implicit to the clinical encounter, despite uncertainty within clinical science. DelVecchio Good (1995, 188) discusses the bridge between the two worlds of clinical science and illness management in terms of ‘clinical narratives’⁵. Within these messages:

“Narrative time shifts from the immediate to the future. And although the future is uncertain, and expressed statistically so, the immediate and mundane have a measure of certainty, of recommendations that are ‘absolute’.” (DelVecchio Good 1995, 188)

Therefore the construction of the clinical narrative, emplotted by a series of technical acts, creates a definitive and competent therapeutic course for the patient - despite an uncertain future.

One such act is the measurement of the blood sugar level. The lack of clear evidence to advocate intensive management of diabetes led Posner (1984, 50) to discuss the regulation of the blood sugar level as a protective ritual to ward off the threat of complications – where the question “How is my diabetes?” is clinically translated as

⁵ DelVecchio Good’s discussion centres on the practice of oncology and the bioscience of cancer.

“What is my blood sugar level?”⁶. Among the health care providers, a variety of definitions of medical management were provided. John described medical management as the following:

“Diabetes management, to me, is monitoring patients for complications and ensuring their blood sugar levels are “normal”.”

In this statement, the blood sugar level has a central role in distinguishing between normal and pathological. In this sense, a ‘normal’ blood sugar level is considered a fundamental component of ‘controlling’ diabetes. The need to achieve a sense of ‘control’, concretely expressed in the blood sugar level, becomes meaningful to both biomedical practitioners and patients in the context of this chronic and degenerative disease.

Expanding upon this definition for management, William added:

“Diabetes management, normally, I think would mean striking up some kind of therapeutic relationship in which you try to educate people about the disease itself. Hopefully, you engage the system so that they can get information about how they can modify the disease. And then you look towards the long term complications and how you can minimize the risk of those developing. That’s what I think of when I think of diabetes management.”

This statement identifies the importance of individual responsibility in management. The notion of uncertainty is ‘minimized’ through management by measurement. In this sense, numbers become a “symbol of certainty amidst the noise of scientific uncertainty”

⁶ In this study the term ‘diabetes’ was often used interchangeably with the term ‘sugar’ by members of the community. Some examples of the use of this term are: “I have the sugar disease”; “I’ve had sugar for four years”; “My sugar has been bothering me”.

(Garvin and Eyles 1997, 64). This passage also outlines the relationship between knowledge and health – where ‘education’ becomes the means to achieve a state of health. As will be discussed in the following section, the assertion that knowledge and health go hand in hand has significant ramifications when the foundation of this knowledge is imperfect. The collision of experience with this expert knowledge becomes expressed in the consequences of living with diabetes. That is, it demonstrates a gap between definitions for ‘health’ emerging from the lifeworld and clinical definitions.

The lack of clear evidence to demonstrate that intensive management will prevent complications does not surface in conversations surrounding ‘appropriate’ courses of action. Among the health care professionals interviewed, 11 individuals stated that they consider the medical management of diabetes successful, if clients comply with recommendations. The underlying message is that good management of diabetes will decrease the risk of complications. According to Andrea:

“When it goes uncontrolled then it leads to a lot of complications.”

Similarly, William stated that:

“There’s a tremendous amount of fear around these complications, and the message doesn’t get out that there is a way, *probably*, to avoid those things.” (emphasis mine)

The use of the word ‘probably’ in this statement identifies a degree of uncertainty regarding the effectiveness of medical management. Nonetheless, rather than focus on the uncertainties regarding the effectiveness of treatment, biomedical discourse centres

on the risks associated with the lack of treatment. Karen highlighted this call to action amidst the uncertainty:

“I think [complications] happen anyway in most people. I think you’re lessening the time. You don’t know if things are going to happen or if they’re not going to happen to you, but if you manage your diabetes better then maybe you’ll get more quality time out of your life, or maybe it won’t happen at all.”

In most statements, the future course of the illness remains largely unpredictable – yet manageable. Unpredictability is the necessary consequence of translating clinical science into diabetes treatment – that is, the uneasiness that results from applying universal ‘truths’ to specific contexts. John discussed this awkward relationship when asked whether the medical management of diabetes prevents or delays complications:

“That’s our understanding as far as physiology goes, but there have been no signs to prove that’s the case. I have diabetics who have poor management, whose blood sugar levels have been high for twenty years who have no complications. That sort of flies in the face of that. I also have patients who are well managed who go on to complications. So monitoring blood sugar is no guarantee.”

This statement calls into question the emphasis in biomedical discourse on reducing uncertainty through the measurement of the blood sugar level. Nonetheless, within this narrative, the category of ‘diabetic’ remains stable despite the apparent lack of stability within its confines. To explain this lack of predictability William described the importance of individual effort in treatment:

“We can tell people that their risk of complications is lower if they manage it. The problem is that they see a lot of people managing it but still going on to complications. Half, or not even half manage it. And what

we're really talking about when we're talking about preventing complications, we're talking about *serious* management. It requires a fair bit of effort." (emphasis mine)

Once again, the category of 'diabetes' and the corresponding treatment regimen are left intact, rather it is individual response to this 'fact' that is called into question.

Despite the certainty of the therapeutic course to be taken, health care practitioners are not offering certain predictions about the future health of the patient.

According to John:

"I put it into a whole package, managing your blood sugar, we expect will minimize your complications. *But there is no guarantee.* So in five or ten years when people have eye problems they're not surprised by it."
(emphasis mine)

This statement indicates that although there is a certain need to manage diabetes in the present, the future impact of this course of action remains uncertain. What is most certain is the need to 'act' and as such fulfilling the moral responsibility of a caregiver.

The material and technical acts required to manage diabetes ground both the client and the health care provider in an 'active' pursuit of health. Nonetheless, previous descriptions of management by health care providers represent 'ideal' scenarios. When asked to comment on how he approaches diabetes management on a day to day basis,

William responded:

"What we do a lot of the time is people come in and we say "Gee, your sugar is high today". That's sort of the sum total of management. And that's most unsatisfactory."

When asked to comment on their interaction with clients regarding diabetes management,

Connor replied:

“Especially with older First Nations patients, they’re real polite and they don’t want to cross you and they so “Oh yes, thank you very much and go away and don’t do anything”. In their interaction with you, they don’t want to make you angry. And the clinics over there, they plan around that day. “Well, I’ve got to get up early, make sure my sugar’s OK”. And they’ll sometimes actually apologize to you, “I completely forgot I was coming today, that’s why my sugar’s so high....because I wasn’t careful this morning like I usually am when I come to see you” (laughs). And that’s a real eye opener because when they’re careful and they come see you, their sugar is 20 and when they’re not careful it’s thirty. I mean that’s not everybody, but there is this idea that they need to please you, and I say that “you shouldn’t be doing it for me”.”

This tension between clinical knowledge and the individual behaviour will now be explored. In other words, what motivates individual management of diabetes?

Answering this question will entail a discussion of the ‘self’ who is considered ‘at risk’.

First Nation’s Management of Diabetes

Contrary to the perceptions of biomedical practitioners, among the First Nations people interviewed the majority stated that they ‘closely’ manage their diabetes. When asked what motivates them to closely manage their diabetes, individuals mentioned both the fear of having to use needles, and also the fear of secondary complications. This fear of having to take insulin injections was articulated by Emily:

“I think the reason why I really watch myself is because I’m afraid of the needles, because I watched my parents take needles.”

Annie also mentioned this fear coupled with the realization that diabetes was a chronic disease:

“I thought a couple of pills and it’ll go away in a week or so. [The doctor] said you’ll have it for life. First comes the pills he said and then comes the needles. Well they said the magic word.”

For a number of individuals there was a tolerance of biomedical interventions to a point – after which the disease itself is considered less damaging than the intervention. Dennis described what his reaction would be to having to take insulin:

“I try to follow up to the best of my ability. Before I wasn’t taking any pills for it. But it got out of hand and I had to settle for pills. And the next round will be the insulin. I told the doctor if it’s up, if it’s going to come to that, forget it, I said.”

A fear of the secondary complications of diabetes was also mentioned in discussions of diabetes management. Margaret discussed these fears:

“I worry about the complications, going blind. But I try not to think about them. It causes stress if you worry too much. Worrying about your blood sugar that causes stress...I didn’t want to end up with losing my feet and eyesight and all that. I figured if I followed the diet and stuff that I wouldn’t get to that point.”

Within this statement, consequences associated with management that exist outside of a biomedical framework are described as important. In other words, the biomedical framework of response focuses on the measurement of a physical characteristic (the blood sugar level). This ‘action’ is intimately related to biomedical definitions that focus on health as a predominantly physical state. In contrast, when placed within Aboriginal definitions for health, stress as a side-effect of management by numbers can be considered detrimental to ‘health’.

Resonating with biomedical narratives, most of the respondents articulated the belief that close management of diabetes would prevent secondary complications or having to use needles. David discussed this perspective:

“Those fears of getting beyond those limits sometimes scare me. What could happen if I go there, if I go too low or too high. But if you keep really looking after everything you shouldn’t have to have that worry.”

As a corollary to this perspective is a sense of individual blame and responsibility if the disease progresses to the point where insulin injections are required or secondary complications occur. This sense of individual responsibility was evident when Doris discussed her brother:

“When he got this care he did ok. Ok, I’m going to exercise, I’m going to do all this. And he did. And then after awhile, he went back to his old habits. And now he’s dependent on needles. See he could have prevented from going to the next step, but he didn’t. So you can prevent it from going to the next step. But no he went back to the old habits. I said, gosh, it kind of makes you angry. Why do you do this when you could have prevented it?”

This statement highlights the moral choices underlying clinical management. In other words, diabetes management is not a morally neutral venture – rather, the concept of the blood sugar level provides a tangible marker on a path towards righteousness. Within this statement, Doris’ brother strayed from this path and therefore is required to live with the moral weight of this decision - expressed in the form of complications. Thus, among those interviewed, there exists significant fear relating to the personal and social costs of getting beyond the prescribed limits coupled with a corresponding sense of blame if one does.

Barriers to Management

According to the health care providers poor compliance with lifestyle changes and a fatalistic attitude towards illness were the most important barriers to effectively treating diabetes. The underlying message in these narratives is that treatment is an individual's responsibility and that barriers to proposed treatment are due to lack of compliance. Barriers mentioned in this study resonate with a previous study on Manitoulin Island which explored the perceptions of clients and physicians concerning diabetes care (Yeates et al. 1996, 9). In contrast, for many of the First Nation's people interviewed, structural constraints and the emotional consequences of living with a chronic and debilitating illness were among the most important barriers to managing their diabetes – despite an articulated desire to manage diabetes. Nonetheless, when disease is conceived within Aboriginal frameworks for health, explicit attention to the physical impact of diabetes is inadequate. In other words, omitting other dimensions of disease - specifically its social and emotional consequences - impedes treatment. Therefore, it is not the disease itself that is the barrier, but rather explicit attention to only one component of the illness experience that represents a barrier to management. Although the desire to manage diabetes is articulated by community members, their inability to do so refocuses discussion to how 'health' in a holistic sense is being impeded. The following section will outline further divergences and consider the underlying concepts of the 'self' that emerge from Aboriginal and biomedical perspectives.

Lifestylism and Fatalism

Among the health care professionals, 13 individuals believed that poor compliance with lifestyle changes and denial of the disease prevented clients from effectively managing their diabetes. According to Beth:

“I think they don’t really take diabetes seriously. Until it gets too unmanageable where say they’ve had a leg amputated or foot amputated. But even then, in a lot of those cases, that person still goes on smoking. And I think too when they’re elders they get more set in their ways as to what they’re going to do, and you can’t tell me to do this and all that kind of stuff. And there’s such an avoidance of having to see a doctor too around here. I don’t know. They probably explain all that to the people. But if they have it set in their mind that, I ain’t going to do a damn thing you tell me, that’s kind of what they’ll do. They don’t really put a value on what the doctor or what the diabetes clinic has told them. They’ll just go back to their own lifestyle, what they know, and what they do.”

In this statement there is a sense that clients act irresponsibly by not taking their health ‘seriously’ and as such can be blamed for their illness. Despite the provision of knowledge – that is, recommendations by experts – there is a sense that individuals ignore advice given. This is a ‘self’ seen as consciously avoiding healthful activities despite being empowered through knowledge. By implication, this is also a ‘self’ that resists institutional authority.

Among the health care professionals, 11 individuals mentioned having difficulty communicating with their clients. According to William:

“But I can tell you that in that six years, there is a cluster of people that I’ve been seeing, once a month or so. It’s always the same. There’s something about the way I’m interacting with them, something in which they see the disease culturally and I’m not able to communicate effectively my concerns about the disease, or generate interest.”

John discussed what he considered to be at the root of these barriers:

“There are cultural barriers, I think mainly because people don’t understand diabetes as a major health problem.”

Scientific knowledge articulates that diabetes is a serious disease requiring biomedical intervention. The above quotes identify seemingly ‘different’ perceptions between health care providers and clients. In this sense, John articulates that the *fact* of diabetes exists, and thus attention to this fact requires active management. Ignorance of this fact - that is, the perception that clients do not view diabetes as a serious health problem – coupled with the obligation to pursue health, identifies a self that resists its moral obligations .

When discussing how perceptions of the disease differ between themselves and their clients, 7 of the biomedical practitioners discussed a fatalistic attitude on the part of clients as a barrier to effective management. Karen described this attitude:

“I’ve been told that ‘when you get your diabetes, you’ll know what I mean’. And I thought, pardon me? And this is by maybe a 40-year-old saying when I get my diabetes. So I think it’s becoming an accepted way of life almost. And like I thought, well actually I’ve been taking care of myself quite well, I don’t expect to develop diabetes.”

Contrary to the ‘self’ described by health care providers which actively pursues health, Jane discussed client attitudes towards treatment:

“I think that part of the problem is that, in many of these families, other family members have had diabetes and it goes past the point of being an illness. It’s almost like a natural part of the aging process. So that the impetus for treating yourself aggressively, it’s not there.”

This idea of normality was repeated in William’s statement:

“Yeah, it’s almost normal when it’s in the family, like “Oh well, she’s diabetic”. Sort of an inevitability about it.”

The subject who perceives ‘normality’ whilst simultaneously being in a disease state further identifies the self as aberrant from a biomedical perspective. Nonetheless, Geoffrey, a health care provider, discussed the structural and historical background of this perceived self:

“Well, I think that basically a lot of the attitude in First Nations communities is fatalistic because they haven’t had control. It’s kind of been zones of oppression in that they haven’t been allowed to make decisions. Someone has told them. It goes back to the old health posters that used to be on the walls, “check with your local physician”. In First Nations you didn’t do anything without accessing a physician. Because everything was against the law, to have traditional medicines, different ceremonies. So as a result you basically taught a dependency. You took away independence and ability to treat oneself and put that all in the hands of the health care system and the physicians. And then they turn around and say, “Why is everyone running to emergency? Why are First Nations always running to the doctors office?”. Because you told them and trained them not to use anything that you couldn’t buy off the shelf. They really disabled individuals in the community.”

Geoffrey’s discussion of a general lack of ‘control’ is significant for the ‘self’ that faces a disease that demands ‘control’ in the form of self-management.

Among the health care professionals, 11 individuals also discussed structural constraints as posing a barrier to effective management. According to Geoffrey:

“A lot of these families are living with minimal income, on welfare so it doesn’t go very far. Definitely financial constraints.”

Nonetheless, 7 of the respondents stated that they did not consider the lack of money to be an issue. According to Karen:

“I think it’s just the choices that people make. You can make bad choices and you can make good choices. If you really wanted to do something I think you’ll always find someone to help you. There always seems to be money for other things like cigarettes and booze and bingo. So I don’t believe all that.”

In sum, within the biomedical narratives there is a sense that the pursuit of health is an individual responsibility. As such, the choice not to engage in healthful behaviours according to biomedical definitions for health identifies a self that is immoral. As will be evident in the following section, a divergent perspective on the ‘self’ emerges when health is defined within Aboriginal frameworks.

First Nation’s Perspectives

The discussion to follow highlights the elements of living with diabetes that are not addressed by biomedical definitions of diabetes and diabetes management. First Nation’s identification of barriers to treatment portrays a different ‘self’ than that articulated in biomedical discourse. The subject position of this self is not deviant but is rather a self engaged in the complex interactions between everyday experience and structural constraints. According to Elaine:

“Yea. It scared me. It scared me to control it. To really look after it.”

The existence of fear surrounding both the disease itself and the ability to ‘control’ it demonstrates that individuals are concerned about management, and that the corresponding consequence of not being able to manage diabetes is significant. Thus, rather than the position of the deviant self previously discussed, the individual who is dealing with diabetes (albeit in their way) has an intimate, as opposed to objective,

knowledge of these consequences. For Dennis, who had recently recovered from cancer, being diagnosed with diabetes had this effect:

“I felt like somebody had stabbed me with a big knife....Now what the hell kind of sickness is this?”

Following diagnosis, a number of individuals mentioned feeling a sense of anger at being told that they had diabetes. This anger relates to a perceived loss of freedom to pursue a chosen lifestyle. Eugene mentioned his first trip to a grocery store following his diagnosis:

“Yea rage. I stopped at the store on the way home from the hospital and aisle after aisle of stuff I perceived I couldn't eat. I thought there's nothing left for me here. But there's lots left. You can't see the tree for the forest. You're looking at all those goodies with miles and miles of sugar.”

David described his feelings:

“I was really, I don't know, I was angry with my doctor around for awhile. I was really mad. I said, what? He says, you're diabetic. This sucks. I hate this right now. He's just looking at me and he says, hey calm down. I'm just telling you, I hate to bring bad news, but you're really going to have to change your tune...I do all this stuff, like say “ok I'll quit drinking, become a better person”, right? And here is what my reward is—what the diabetes? Come on man, if there's a God up there, when I get up there, I'll kick his ass. That's how I felt. I felt really, really angry. Disappointed. Sad. Resentful. Just a lot of different things. All negative mostly because look man what the hell, I'm doing all this, and this is how you repay me, fucker. I don't know, I was really, really angry... I've been living a pretty good healthy lifestyle compared to others. It should have probably struck them more first but it didn't, it hit me first. That's just a fact I hate. I can't accept it....It's really frustrating because these guys run their bodies to shit all day long whatever, don't eat or drink for 4, 5 weeks straight.”

David conveyed a strong sense of injustice, where despite his individual efforts to change his lifestyle he is still unable to achieve his desired state of health. With the onset of a

chronic illness, such as diabetes, health becomes an unattainable goal. David described the position he now finds himself in:

“Yea I’m ashamed of it. I don’t want to have it. I only thought it would be someone’s disease like when they’re 50. To affect someone as young as me, it just sucks.”

Denial as a response to being diagnosed with diabetes was also mentioned by most respondents. Raymond defined what he meant by denial:

“I go a lot of days without thinking about it. I take my medication, block out that I have diabetes. Sometimes I think about it. When I go to see the doctor, that’s mainly when I think about it. Sometimes if I wait to long for a meal or a snack I get the shakes, then I think about it.”

When asked to characterize this denial, Annie responded:

“It means I wish I never had it. Or why is it me? Then I have bad days. Then I have good days. But I try and not think about it. If I have a sore toe, I panic because I don’t want my foot cut off. And I’ve seen so much of that. You hear so much about it. It’s just what would I do, what would happen...I lose my arm or gangrene this, this, this nonsense. Not nonsense, but this should happen because it all goes back to diabetes. Everything. Everything goes back to diabetes.”

Dennis described what he felt was at the root of this ‘denial’:

“I don’t know...People who have diabetes just don’t care anymore because there’s no way to cure them anyway.”

This statement could be interpreted as a fatalistic attitude, yet it can also be interpreted as a form of grieving. In other words, it represents a response to the ‘loss’ of normality in one’s life. The occurrence of diabetes throws ‘order’ into question and thus responses to diabetes, such as denial, are directed towards re-establishing this order.

Margaret discussed denial of the disease relating to the stringency of required lifestyle changes:

“I think their diet, of what they’re supposed to eat. I think that’s why I denied it. I had to go on this special diet. I didn’t know there was meals out there you can have that aren’t as bland as years ago.”

The social consequences of lifestyle changes were evident when Gregory discussed not wanting other people to know:

“So if you’re doing something you shouldn’t be doing, people will come and tell you, hey you’ve got diabetes, you shouldn’t be doing that. So you don’t like people telling you all the time. You know what it is. You don’t have to be reminded. So you just don’t say anything. You keep it to yourself and hope nobody finds out”.

Additionally, Gloria mentioned the need to resist being labeled ‘sick’:

“I think there’s denial around a lot of things because everybody’s Indians don’t get that, Indians don’t get that. That we’re curable for everything. That there is nothing wrong with us. This is how you are type of thing... They don’t like the label I guess.”

When asked to discuss difficulties associated with living with diabetes, 9 individuals mentioned economic costs. Margaret discussed her own difficulties maintaining the proper diet:

“You can live with it and have a decent life. But sometimes it’s hard for us in the middle of the week is our hardest part because we’re both pensioners. We have no source of income to fill the gap between the end and the first of the month. So when you run out of things... I try and buy enough to last from month to month, but then something always happens... we don’t always have those four things that you need to have in a meal.”

Gregory outlined these same problems:

“I think for one thing is not eating properly. Not having the right foods for your system. I mean you have to have all kinds of vegetables. A lot of people can’t afford these things. They just eat potatoes dipped in grease. Some people just don’t have the funds. A lot of people that have jobs, they can afford stuff, but a lot of people don’t. And then you don’t have a job. You’re living from one welfare day to the next. And that’s stressful. Nobody wants to be on welfare. Everybody wants to work. But a small reserve like this, there’s no work. Only certain people work and the rest of us have to sit around... They have health clinics but when you go home, what are you going to eat? This is what you’re supposed to eat. Well, hey listen, I’ve only got so much in my welfare cheque and I can’t afford all this fancy stuff.”

In this statement, there is a sense that the social and economic realities of life on a reserve impede personal worth that is reflected in the ability to work.

Yet some individuals explicitly mentioned that they do not feel that the lack of money is an issue. According to Sylvia:

“Oh I think they can, it’s just that they don’t put out the money because they want to get this. So material. I really believe people here or any community can really afford what they want to get. But groceries, their grocery list goes down even more, and they don’t get what they should get.”

Thus individual lifestyle choices, remain an important dimension of diabetes management for some First Nations people.

In sum, in both biomedical and community narratives a key theme that emerges is the desire to achieve ‘normality’ in the face of illness. Nonetheless, normality and its pursuit are defined differently within these two frameworks. According to biomedical narratives normality is achieved through the measurement of the blood sugar level. The motivation to manage within this framework is based on *uncertainty* regarding the implications of poor management such as the potential to develop secondary

complications. In contrast, community narratives focus on the social rather than the physical consequences of living with diabetes. For community members, it is the loss of freedom associated with the onset of diabetes that needs to be redressed in order for 'normality' to be achieved. Thus the concept of normality is not the absence of physical disease but rather the ability to maintain order in the lifeworld. This order is contingent on defining away the social consequences of diabetes and explains responses to diabetes such as denial and a resistance to being labeled sick.

Health and Individual Responsibility

The emergence of the *White Paper* (1974) posed a challenge to the traditional sickness/cure/care framework for health policy through its expansion of the definition of the determinants of health to include: lifestyles, environment, human biology, and health care organization (Evans and Stoddart 1990, 1347). In this framework, health care was reconceived in terms of broader steps to improve health. Nonetheless, two possible directions for health policy emerged from this report. One direction involved focusing health policy towards more comprehensive social reform, whereas the other interpreted individuals as being responsible for their lifestyle and therefore their health. It is the latter explanation that took precedence and directed health policy towards an analysis of 'individual risk factors' (Evans and Stoddart, 1990). This perspective is evident in the response of health care practitioners to diabetes treatment, where the medical framework is considered effective and that rather it is an individual's choice to comply with these recommendations that will determine the course of the illness.

Among the health care professionals interviewed, 13 individuals mentioned that treatment is essentially an individual's responsibility. According to Nancy:

"It's their life. It's their health. It's not mine. All I can do is support them and tell them what's right, what would make a difference."

Similarly, Karen stated that:

"It's a person's decision. I think it's their ultimate decision. And it can be anybody's. If they don't choose to take my advice, then that's sort of your choice."

The medical construction of diabetes has created a population "whose health is endangered in a common, though individualized way through the concept of 'risk'" (Harding 1997, 141). Therefore, all individuals located within the universal category of 'diabetes' are at risk for developing complications. As a participant in society, individuals are given the option to pursue health as a resource for living. Nonetheless, current health promotion literature also articulates an individual's obligation to pursue health in order to be considered a responsible member of society (Nettleton 1997, 208). The implication is that each of these individuals has not only the *right* but also the *duty* to manage diabetes and prevent future illness.

The 'self' to which biomedical discourse speaks is autonomous, subjective, and active and maintains the position that it is "the individual who is best able to make his/her life better" (Nettleton 1997, 208). It is the practices and recommendations of experts in the health sciences that both define and create the possibility for health. In other words, experts assist in the process of understanding the self. In this context, the

subject is constructed actively, yet never through processes that are autonomous or independent of culture and society (Foucault 1990, 11).

The premise of this approach to the self is that through the process of self-transformation, the individual has the capacity to prevent further illness. According to Greco (1993, 361):

If the regulation of life-style, the modification of risky behaviour and the transformation of unhealthy attitudes prove impossible through sheer strength of will, this constitutes, at least in part, a failure of the self to take care of itself – a form of irrationality.

From the viewpoint of clinical rationality, control of the self can be equated with control of diabetes – where the ability to manage diabetes is considered a reflection of the ability of the self to be successful.

Despite the emphasis on individual risk factors with respect to policy, evidence exists that seriously challenges this perspective. The Whitehall study indicated that social class gradients in mortality remain after controlling for individual risk factors (Wilkinson 1996, 53). This evidence strongly suggests that an approach based on individual risk factors is inadequate and that what is required is a response to these individual risk factors at a societal level. According to Harding (1997, 143):

“The political significance of this conceptualization of health is that it is formulated as a series of common endpoints for groups and individuals, obscuring their sheer impossibility for some.”

In any framework for health there is a need to consider the impact of cultural and societal practices in shaping and defining the backdrop against which different actors

are then required to perform. In other words, healthy lifestyle practices are more or less attainable depending on the subject's position in society. This position is supported by studies of diabetes management where Chaturvedi et al. (1996, 427) discovered that there is a correlation between good glycemic control and a higher socioeconomic status. Additionally, socioeconomic differences in diabetes related complications were found, to an extent that can not be accounted for by improved glycemic control (Chaturvedi et al. 1996, 429). This evidence suggests that a more adequate framework for health would focus on the environment that establishes the level of exposure to 'risk' rather than directing resources towards new services to cope with high risk people, perceived as individuals responsible for their own fate.

Conclusions

“For tightrope walkers everywhere, trustfulness of the rope is a certainty that comes out of discipline, to others, it is just a rope.” Jeanette Winterson

Jeanette Winterson, in discussing the potential perils associated with tightrope walking, has illuminated a key element in our discussion of the appropriateness of frameworks for health that are founded on the concept of 'risk'. In this case, *certainty* is a result of 'discipline', or in other words expert knowledge, rather than it being an inherent quality of the rope itself. For those lacking this expert knowledge, the rope is just that – a rope. Nonetheless, this position does not imply that the rope itself is benign,

for were a 'non-expert' to embark on a tightrope expedition, one can only imagine the consequences.

The certainty that the discipline of medicine asserts is the need to 'act'. Castel (1991, 283) discusses how in the face of unpredictability:

“It is better to act , since, even if unfounded intervention is an error, it is one that will certainly never be known to be such; whereas if one abstains from intervening and the threatened act should still materialize, the mistake is obvious and the [doctor] is exposed to blame.”

Therefore a call to action abdicates moral responsibility on the part of the doctor by shifting blame to the 'non-complier' and obfuscates the structural conditions – specifically political, economic, historic, and societal - whereby some individuals are more able to 'act' than others. It is not surprising that risk reduction focuses on lifestyle, which is considered modifiable, thus obscuring factors not amenable to change at the individual level (Lupton 1995, 85).

The construction of new categories of risk concomitantly creates new targets for preventive interventions (Castel 1991, 289). Following membership into the universal category of 'diabetic', two possible subject positions are identified: an individual who is empowered through knowledge and actively managing their diabetes; or an individual who is disempowered and misinformed (choosing to either ignore advice given, or not having access to this information). Nonetheless, the medical position that perceived susceptibility to risk will necessarily motivate behaviour (Harding 1997, 141) is questioned by individual response to this knowledge. This position is evident in

Karen's description of a lack of trust on the part of clients towards the advice given by biomedical practitioners:

"It's kind of hard to explain, but when I have a patient, yes I think of their cultural background, but I do that for every individual patient. So that's always a part of your background. But I don't make a distinction that you're different from me, whereas I'm different. Even things that I tell people that are written in literature, that doesn't matter, because whatever is written isn't as good as what like let's say your elders might have said. Like scientific proof doesn't seem to hold much weight."

What is often obscured in the medical literature is that the consequences of suggested actions are not necessarily neutral but have numerous human and social consequences. These consequences are evident in the level of fear surrounding insulin injections and secondary complications along with the emotional consequences of being diagnosed with diabetes. On another level, however, these consequences highlight how illness throws personal meaning into question. In other words, it leads Annie to wonder: "Why is it me?" and David to state: "I'm doing all this, and this is how you repay me?". In order to cope with the loss of freedom that diabetes represents, when defined in a biomedical framework, individual responses are focused towards minimizing and coping with its social consequences. These responses include denial and stress. Nonetheless, in the realm of diabetes treatment it is not the above mentioned consequences but rather the consequence of poor management and thus progressing to secondary complications that is of concern to biomedical practitioners. Thus, it can be argued that the concept of freedom becomes redefined for an individual with diabetes, into a freedom to exercise technique towards the pursuit of health (Grant 1969, 137).

Closing the discussion it is necessary to briefly examine what potential options this ‘freedom’ provides. The choices left are perhaps limited, although extensive, in their implications. The first option is the use of ‘intensive management’ for diabetes, resulting in eventual treatment with insulin therapy, and thus represents the most ‘active’ approach. The consequences of this approach parallel with Harding’s (1997, 135) discussion of Hormone Replacement Therapy, where diabetes management will result in a market for consumers requiring pharmaceuticals, in addition to subjecting individuals to increased medical surveillance. The benefits of ‘intensive management’ remain uncertain and thus these potential implications are considerable. The second option is an approach that focuses exclusively on lifestyle related risk factors, thus creating interventions at the level of daily life. Although a healthy lifestyle is, theoretically, a desirable goal, the differential ability of individual subjects to attain this goal is consequential. Underlying both of these approaches is the individualization of the problem of diabetes – a phenomenon that is, statistically speaking, a collective occurrence. The implications of these two approaches create an impetus to explore alternate possibilities for health care planning. The following are recommendations for future health care planning surrounding diabetes diagnosis and management:

- The emotional consequences of being diagnosed with and living with diabetes should be considered potential barriers to both prevention and treatment. Additionally, the emotional consequences associated with the circumstances surrounding diagnosis should be considered.
- The potential for fear surrounding diabetes and its associated complications to immobilize rather than inspire individuals to effectively manage diabetes should be considered in future health care planning.

- Health care planning should contribute towards an environment where diabetes management is considered an achievable goal by individuals with diabetes. Within this framework, health promotion would be achieved through an emphasis on community development rather than individual lifestyle choices.

The following chapter will explore this nexus between individual and collective definitions for the 'problem' of diabetes through a discussion of causative factors.

Chapter 4: Understanding Diabetes: Different Causes?

“Little progress has been made in understanding the pathogenesis of non-insulin dependent diabetes mellitus. Although the disease runs in families, modes of inheritance are not known...The author favours the view that an islet cell abnormality is primary and necessary for the development of diabetes but that acquired insulin resistance, usually obesity-related, is required for overt hyperglycemia to develop.” Harrison’s Principles of Internal Medicine (1991, 1742)

“The obesity – I find a lot of the diabetics are overweight and a lot of them don’t exercise, a lot of them smoke. So to me it’s kind of all interrelated. Probably eating a poor diet which probably leads to them being diabetic – a lot of greasy foods and stuff like that – store bought foods.” Beth, Health Care Provider

“They say it’s hereditary but I’m not quite sure. I think it’s ... like we probably all have the natural weak gene that causes diabetes. It just depends on the lifestyle that you live in order for it to kick in. Maybe I was pushing mine so far that it maybe took long enough to really break it down finally and said, ok well, I can’t handle all this sugar....All native people live a stressful lifestyle. Trying to cope in a society that’s not traditionally like the way we used to follow, so we changed that a lot. And not eating the proper foods that we used to eat. My dad says if it doesn’t run, don’t eat it. If you can’t catch and kill it, don’t eat it. Or if it doesn’t swim fast, don’t eat it. Or if it’s just standing there, then it’s probably lazy meat you’re eating. And all the other things. Like we never had sugar or sweetness. It used to come in only in berry form in the summer. The other sweetness we used to get was in the spring time with maple syrup only. That would just be once to cleanse the whole system or whenever for that season. If you drink enough syrup whatever, it just goes right through you. And that’s all the sugar you would get for the next long while. So lifestyles one of them. There other thing is because of contact and change and influence from non-native society, there’s different foods come in that play like look at all these black forest cakes and stuff. These guys are eating it and their body, like for ten thousand years it was only eat meat with no salt or berries and stuff like that. Food that they come is all different and there’s different ways of cooking it. And a lot of it is frying. Just clogs you all up and everything. It just causes poor circulation. On top of it you’re jamming sweets in there. There’s something else to pump through. It’s like running a garden hose, pouring oil and pouring sand and grass and gravel in there trying to make that hose run clean. That just doesn’t work when you’re so used to just having water run through it. So I think it is probably a lot of the foods. But at the same time too there’s another introduction of alcohol which gets to a lot of these people. Their lifestyles are all fucked up. They don’t have a job. There’s no community support like to

find work. There's nothing to do except get into a state of depression, they're eating junk, they're unhealthy, they're getting fat, lazy, and stupid. Then they're starting to drink on top of that. Then they get drinking. Oh that's an escape for a little while and then it becomes like their reality after. On top of that there's a lot of sugar in alcohol and stuff like that. So all those things mixed. Like they're not all going out spear fishing, hunting, or catching what we used to catch to eat that would maintain their body health. So they're just sitting around drinking. Inactivity that clogs you up even more. On top of the alcohol it's really screwing up a lot with you too. So there's three major factors and all of a sudden diabetes is hanging around waiting for somebody to get all fat and lazy and whatever saying there's my next victim. The only thing is there are others like myself that have been constantly working doing stuff all the time, eating right, and then it affects so there's probably a genetic thing there too." David, community member.

The last chapter focused on biomedical practices surrounding diabetes and their corresponding impact on the lifeworld. I proposed that the construction of diabetes from this perspective as an 'individual problem' requiring active management has numerous consequences – both on a societal and an individual level. What remained unspecified in the previous chapter was how this perspective excludes teleological implications of the illness experience. In other words, the disorder in one's life caused by illness throws meaning into question. According to Sontag (1989, 22) it is not the disease itself but rather its 'mythologies' that creates this crisis in the self.⁷ Thus, in the case of cancer where the repression of emotion in oneself is considered to be causative (Sontag 1989, 22), coming to terms with the illness involves delving into larger issues of the

⁷ Susan Sontag's book *Illness as Metaphor* (1989) is useful in highlighting 'metaphoric linkages' that structure the illness experience – specifically, tuberculosis, cancer, and AIDS. Nonetheless, Sontag's (1989, 3) project which states that: "Illness is *not* a metaphor, and that the most truthful way of regarding illness – and the healthiest way of being ill – is one most purified of, most resistant to, metaphoric thinking" rests on a definition for disease as objective biological fact. In contrast, this thesis

self's 'place in the world'. In this sense, individuals must respond to the threat to the 'self' posed by the illness experience (Fife 1994, 309). How people understand the *cause* of their illness can be considered a response to this threat and is therefore an integral part of re-establishing order. This chapter will outline perceptions of causal factors for diabetes on the part of both biomedical practitioners and community members.

The above quotes represent three divergent perspectives on causality, each embedded within conceptions of health. Both the first and the second quotes provide biomedical explanations and thus health is defined as a physical state. The third quote provides a community explanation and is founded on a holistic definition for health.

A number of potential causative factors are outlined in the clinical literature. The first quote, taken from a text on internal medicine, both genetic and lifestyle-related factors are outlined. A degree of uncertainty is articulated over the relative importance of each. Nonetheless, this author favours the position that there is an underlying biological abnormality that is then confounded by the presence of lifestyle-related causative factors.

When clinical literature is translated into biomedical practices surrounding diabetes an emphasis on causative factors that are amenable to change emerges. Within Beth's narrative a number of causal factors for diabetes have been described including: obesity, a lack of exercise, poor dietary practices and generally poor lifestyle choices such as smoking. Each of these causal factors are lifestyle choices that can cause illness

contests the 'objectivity' of this definition, arguing that definitions of disease are historically contingent

in the body. Implied in this statement is the perspective that poor health is a physical condition resulting from of an individual's choice to engage in activities that are deleterious to health. Therefore, perceptions of cause influence what health care providers consider to be appropriate 'activities'.

When juxtaposing David's narrative with Beth's it is evident that a different perspective on health - and as a corollary, the causes of disease - emerges. Within David's passage, the onset of diabetes is attributed to a number of related issues. Much of this narrative centres on change – alternating between descriptions of past lifestyles and contemporary ones. This narrative identifies that the contemporary lifestyle has a detrimental impact on Aboriginal people. David also articulates that the contemporary lifestyle is different due to contact and its concomitant changes. The passage describing the past use of Maple syrup as a cleansing substance, and the current relationship of sugar with sickness – could be read as a description of the purity of the past in light of what appears to be toxic conditions in the present. This narrative also suggests that the impact of this change has led to alcohol use and a lack of community support.

Within David's narrative there is a perception that the combined effects of these external factors on Aboriginal people and their bodies is resulting in the onset of diabetes. Diabetes as such represents an inherent (yet hidden in the form of a 'weak gene') quality of these individuals waiting for the right conditions to make an appearance.

(see Chapter 1).

Within David's narrative, Native bodies are defined as different, evolving in a different environment. This contributes to the toxicity of the contemporary lifestyle in relation to these bodies. Thus, in sum, diabetes is a phenomenon that has its roots in a particular socio-historical context and is having a collective impact on Native bodies.

There is, however, a contradiction at the end of this passage David describes a position very much in keeping with Western views on sickness. David states that in his case, where he has actively pursued an improved lifestyle, the cause must be purely genetic. In this sense, the basis for David's illness is largely biological and therefore not preventable through any actions of the 'self'. Locating illness explicitly in the body, leaves in tact the concept of the 'self' and the possibility that individual choices could have prevented the occurrence of illness (Garro 1994, 115). Within David's assertion the unhealthy, and by implication, irresponsible self is transformed into a 'self' whose health is purely a result of biology and thus not morally bound to assume responsibility for its current illness.

Underlying each of these perspectives is a sense of *morality* surrounding the actions of the self in relation to health. The moral basis for this action is closely related to how health is defined and thus we have two divergent moral tales. The biomedical narrative can be equated with the modern "morality play" whereby humankind acts in ignorance, falls from grace, and is redeemed through the pursuit of 'proper' and 'moral' decisions (Garvin and Eyles 1997, 66). Within this story of causation the initial ignorance of Aboriginal people in relation to their health has led to their corruption, as

manifest in diseases such as diabetes. Following this fall from grace the individual repents, through seeking health care and the adoption of the 'sick role' (Parsons, cited in Turner 1996, 38). Redemption then occurs through the moral exercise of free will – specifically referring to an individual's choice to 'live healthy' according to biomedical definitions for health.

In contrast, the moral choices that emerge in David's narrative can be equated to the concept of the foundational myth. In this sense, human beings have been removed, through external pressure, from an initial state of purity and strength. In other words, Aboriginal bodies existed in a natural state of 'health' pre-contact - a state that has since been disrupted. A 'moral life', implying the pursuit of health, therefore involves a return to 'Eden'. This chapter will outline the implications of perceptions of cause in informing 'moral' action surrounding diabetes. The following section will outline general distinctions between lay and professional understandings of health as it is these underlying beliefs that form the foundation of a 'moral' course of action.

Lay and Professional Perceptions of Health

Within the literature a number of differences have been noted between lay and professional understandings of health. Stacey (1988, 142) emphasized that much of the early literature on 'perception' was based on the problematic assumption that biomedicine was correct and that lay people were ignorant (for an example see Furnham 1994, 715). Thus lay understandings of illness were considered important to increase compliance in health care – a form of redemption within the morality play - rather than

considering these beliefs as valid in their own right. Although lay perceptions have been described as ‘illogical’, Stacey (1988, 152) nevertheless emphasizes that the logic underlying lay beliefs is evident when the “believers are located in their social context.” In this sense, societal values are enmeshed in lay perceptions of health and therefore contesting definitions for the ‘causes’ of illness can, in part, be considered expressions of societal conflict.

In general terms, professional understandings of health have been said to focus on the disease process whereas lay understandings focus on the personal experience of illness (Brown 1992, 267). Within a biomedical framework the concept of disease is both normalized and universalized. These processes are well described in Smith’s (1981, 348) article outlining contesting definitions for ‘black lung’ - a disease affecting coal miners. As a medical construct, black lung was thought to be caused by ‘coal dust’ – a definition in line with the emergent germ theory (Smith 1981, 345). Within this framework, causative factors associated with the social and economic environment were excluded. Preventing the occurrence of black lung became a question of controlling a physical object. The collective problem of black lung – related to the poor working conditions of the miners - was thus obscured within a biomedical framework.

Nonetheless, struggles against dominant medical definitions are evident in lay perceptions of health (see Smith 1981, 343). As mentioned in the previous chapter, there are numerous consequences to being defined as ‘ill’ - namely that it involves setting oneself apart from society. Remembering that definitions of health have moral

implications, this 'setting apart' can be considered a form of deviancy. In other words, "it makes being not ill very important" (Litva and Eyles 1994, 1085). The moral implications of definitions for health become particularly important in the context of chronic illness, where people can not *get* well and therefore negotiate the terms of their illness so that they are acknowledged as *being* well.

In order for individuals to be healthy, when affected by a chronic illness, the illness must either be ignored or 'defined away' (Litva and Eyles 1994, 1085). This perspective is evident David's discussion of the causes of diabetes, where he resists viewing himself as responsible for his illness. Causes of illness that are beyond an individual's control and thus outside the self are more tolerated. Blaxter (1983, 65) in a study of health perceptions among Scottish women found that only in very few cases were women willing to admit that disease was self-inflicted. In contrast, women preferred to describe illness as caused by infection or heredity. When defined in relation to the self, 'being healthy' involved being unstressed and able to cope whereas health in relation to others was viewed as 'not being ill' (Blaxter 1983, 64). In this sense, people define away illness for themselves if they are able to cope with life yet may be judgmental of others.

This section has described general differences between lay and professional definitions for health. The remainder of this chapter will focus on definitions emerging from the study. In order to highlight the divergences between these two perspectives it

will be beneficial to outline a specific framework from which the concept of causality will be approached.

Social Causality

The usefulness of causal theory to the social sciences has been much debated. The law of causality has been compared to the monarchy – surviving only because it “does no harm” (Russell, cited in Hage and Meeker 1988, 1). Nonetheless, Hage and Meeker (1988, 1) state that the ‘why’ of social life has both practical and theoretical implications – equating the success of policy interventions to the ability to understand relations between variables. Hage and Meeker (1988, 12) relate the limitations typically associated with causal thinking to the dominance of the statistical technique of path modeling. Underlying this approach is the problematic assumption:

“That the only phenomenon that can be thought about causally are those for which data can be collected that meet the statistical assumptions of the model” (Hage and Meeker 1988, 12).

It is through the separation of the ‘causal hypothesis’ from the evidence by which it is tested that the potential to overcome these limitations becomes possible. In other words, limitations in measurement may prevent direct observation and therefore social causality should be conceived as a theoretical link between cause and effect.

In order to explore this theoretical link, Aristotle’s causal criteria will be used to discuss Aboriginal and biomedical perceptions of cause. In his Metaphysics (bk1, ch3) Aristotle states:

“There are four recognized kinds of causes. Of these we hold that one – the formal cause – is the essence or essential nature of the thing (since the “reason why” of a thing is ultimately reduced to its formula and the ultimate “reason why” is a cause and principle); another – the material cause – is the matter or substrate; the third – the efficient cause – is the source of motion; and the fourth – the final cause – is the cause which is opposite to this, namely the purpose or “good”; for this is the end of every generative or motive process.” (cited in Hage and Meeker 1988, 2).

Science is concerned with what puts events in motion and thus makes exclusive use of the third– the efficient cause (Hage and Meeker 1988, 2). Nonetheless, in everyday life people invoke causal explanations that venture beyond this realm. The discussion to follow will discuss the range of causal factors invoked in explanations for diabetes – namely the formal cause, the material cause, and the final cause.

The Efficient Cause: Biomedical Narratives

Among health care professionals, 16 people attributed the occurrence of diabetes to individual lifestyle factors. According to Karen:

“I think people’s eating habits, their exercise, their weight. I think it’s more things that you can control that are out of control that’s causing the high rates.”

Implicit in this statement is the belief that it is within an individual’s capacity to prevent diabetes. A direct link between a lack of control and causation was also articulated by Nancy:

“I think because of lifestyle issues. I think the diet is very important. This would take a long time to change. There’s a lot of people who eat a lot of fat. It seems to be their favourite food. Some people don’t want to change that.”

Underlying this statement is the view there is a resistance to change on the part of her clients. The concept of change, as such, emerges in many of these narratives. Michael discussed the relationship between lifestyle factors and an increased occurrence of diabetes:

“At the same time as it increases, people are probably moving farther away from an active lifestyle...Everything else is useless if people don’t follow the lifestyle changes.”

This statement articulates that the lifestyle of Native people has changed, and that this change is directly related to the onset of diabetes. Nonetheless, an emphasis on the need to make lifestyle changes, places the burden of causation on the shoulders of the individual. Beth had a similar perspective:

“I know around here, even in our workshops and stuff, we always try to stress that these people have such a sedentary kind of lifestyle now that this is bound to happen.”

This statement resonates with Michael’s – emphasizing that it is a sedentary lifestyle that is causing diabetes and thus within an individual’s capacity to prevent. In this sense, the conditions that might promote this ‘sedentary lifestyle’, beyond individual responsibility, are obscured. When asked what has caused this transition in lifestyle, Beth gave the following response:

“Well you can’t really say that, oh it’s the white people that have brought this disease here. But it’s something that came along because of the changes in the diet. You can go back a long time ago with fur traders and fur trading for sugar and lard and all that kind of stuff. These are things that native people never had. And the flour and all that. So it kind of resulted in them eating in a different style. Later on not needing to go hunting and fishing and kind of just buying all their food supplies.”

Within this statement there is an acknowledgement that Westernization has played a part in these changes and their corresponding impact on Aboriginal peoples. Nonetheless, the majority of narratives emphasized individual responsibility and re-iterated the lack of personal control over health. As a corollary to the transition to a sedentary lifestyle, 12 of the health care professionals discussed obesity as a causative factor. According to John's observations, there is a direct relationship between the two:

“I think obesity is a factor, you see more diabetes in the Native population and you also see more obesity.”

Thus, in this statement there is a direct relationship between cause (obesity) and effect (diabetes). Charles expanded on this relationship and discussed where to focus health care initiatives:

“I think probably one of the most important things we can teach them is weight control. You don't see a lot of skinny diabetics. You also find that a person who is moderately obese who develops this kind of diabetes, if they got their weight down, they could control it.”

This response clearly emphasizes a specific need to target individual lifestyle factors in order to prevent diabetes.

Genetics was also mentioned as a causal factor. John emphasized that:

“I think with most cases the cause is genetic.”

William re-iterated this perspective:

“Well, there's a big genetic component. There are people who, with the right set of circumstances, are going to get it no matter what.”

William's statement recognizes that in certain cases, the individual ability to control the onset of illness does not exist. Importantly, both John and William placed more emphasis

on lifestyle factors as causative, yet their additional mention of genetics as cause is revealing. I would suggest that the discussion of both lifestyle and genetics as causative relates to the multifactorial etiology of diabetes described in the medical literature. The contradictions underlying these two perceptions of cause – namely that diabetes *is* or *is not* within an individual’s capacity to prevent– are resolved, in practice, when faced with the need to ‘act’. An emphasis on those causative factors deemed modifiable provides a framework for moral action surrounding health. Nonetheless, some of the health care professionals explicitly identified being skeptical about the importance of genetics in causation. According to Karen:

“I don’t know if you can say genetics. I know a lot of people have said that they think there’s a genetic link. I personally kind of looked up some things and I don’t really know if I tend to believe that.”

In sum, although the clinical literature outlines genetic and lifestyle-related causal factors, in practice an emphasis is placed on lifestyle factors – specifically, obesity. When framed within the concept of the *efficient cause*, diabetes results from an individual’s lack of control over lifestyle factors. In moral terms this lack of control represents a ‘fall from grace’. Although the relationship between cause and effect seems reasonably direct in the biomedical narratives, the mention of genetics as causative highlights a degree of uncertainty surrounding causation – an uncertainty that is also reflected in the clinical literature. That is, it indicates the lack of a direct cause/effect relationship between diabetes and its onset and an inability to definitively attribute its occurrence to individual responsibility. These apparent contradictions, however, resolve

themselves in practice where an emphasis on those factors deemed modifiable provides a tangible framework for action.

Beyond the ‘Efficient Cause’: Community Narratives

The following section will outline what community members articulated as causes of diabetes. These causes venture beyond the realm of the efficient cause and invoke meanings based on Aristotle’s three other causal criteria: the formal, the material and the final. Woven together, these causal explanations form a story of causation that closely resembles the idea of a foundational myth. Within the narratives, causal factors fall under the general categories of: genetics; dietary change; chemicals and pollution; stress; alcohol; lifestyle issues; and obesity. It is important to mention that for many individuals a number of causes were outlined.

I will begin with the two most frequently cited causes: genetics and dietary change. Upon first inspection, these two causes seem to be in opposition: that is, one represents a biological explanation and the other an explanation based on societal change. Nonetheless, over half of the people who discussed genetics, also discussed dietary change as a causative factor. When asked which factor was most important, genetics was chosen.

The Formal Cause: Genetics

Approximately 20 of the respondents outlined genetics as a causative factor. There did not appear to be differences between diabetic and non-diabetic individuals.

Enmeshed in the discourse surrounding genetics as cause is a sense of inevitability surrounding the onset of illness. This inevitability is articulated by Emily:

“My sons have a friend that is diabetic and he kind of got it at a younger age. And they were kind of really shocked about it I guess when they found out that he was diabetic. I had to pass on my information to him from what I know what causes diabetes. They kind of understood it. They understood what they meant by when I said that it's hereditary. So then they were telling me one day, they said, well eventually we'll all probably be diabetic then.”

David, a young man from Whitefish River, discussed his concerns:

“I was aware of it and I was thinking it's hereditary and it's the family. I'm wondering who's going to get it. Who's ticket is up.”

In each of these statements, a sense of powerlessness relating to the onset of diabetes is evident. Related to this powerlessness is a further lack of control once the disease occurs.

Jesse from Whitefish River explained this lack of control in greater detail:

“Everybody has it. The only thing is it comes out in some people, and some people it doesn't come out. And some people will say, oh I have borderline. There's no such thing as a borderline diabetic. It's either you have it or you don't have it. If it decides to come out, it'll come out.”

In this statement diabetes is described as an inherent quality of individuals that will emerge under certain circumstances. It also represents a force which the individual has no ability to mitigate. Implied in this statement is the belief that this force will differentially affect individuals – specifically that diabetes will decide to come out in *some* people.

Remaining unspecified is *who*, in particular, will be affected.

Re-iterating this lack of control in the face of illness, Eugene stated:

“I figure like I said I may have contributed but I feel that's beyond my control. It's like aging. There is nothing you can do but you can age gracefully or you can age too fast. You can mitigate against it but you can't really stop it.”

In this statement, Eugene makes an analogy between diabetes and the aging process.

Aging as such represents a ‘natural’ if undesirable part of the lifecourse. This relationship between diabetes and what is ‘natural’ was further elaborated by Elaine:

“I just got it recently, up until maybe 3 or 4 years ago. I was fine all that time. It runs in my family. My mom has it. And it also ran on my dad's side. My grandmother has it. So it probably just came *natural* for me. I don't know.” (emphasis mine)

In this sense, a discussion of genetics as cause naturalizes the occurrence of diabetes for certain individuals. Who precisely is affected becomes significant in informing what action can be taken to prevent diabetes. Gloria specified directly who is affected when asked about prevention:

“I think in our community it's not preventable but I think people can live with it in a healthy way. Because we have so many people and they're of course like diabetes could be a genetic disease as well. Like if your parents have it or whatever, maybe two generations down the line. They're more susceptible to getting diabetes. So I don't think it's really preventable.”

Therefore the corollary to the role of genetics in causation is that diabetes is also not preventable. This perspective contrasts that of the biomedical practitioners.

The story emerging thus describes cause in terms of Aristotle's ‘formal cause’. The formal cause refers to attributing cause to the ‘essence of being human’ (Hage and Meeker 1988, 4). Within these narratives the formal cause is the biologically determined Native body. The possession of such a body does not, however,

deterministically result in diabetes. In other words, the occurrence of diabetes in this body is not tautological, rather additional causal factors are required for diabetes to occur. These additional factors will be further outlined.

The Material and Efficient Causes:

The Contemporary Lifestyle and Processes of Change

Individuals who are genetically predisposed are thus naturalized into the category that has been referred to as the ‘formal cause’. Nonetheless, diabetes is *triggered* by circumstances in the external environment – conditions that can be considered a ‘material cause’. It is this relationship that I would argue led many people to identify *both* genetics and dietary change as causes without perceiving any contradictions. That is, when inserted into the lifeworld, what initially appear to be diametrically opposed explanations are brought together to explain the occurrence of diabetes. According to Cyndy:

“I would probably put genetic at probably about 80%, maybe 20 at lifestyle. That’s just my own personal belief.”

The relative emphasis on genetics identifies diabetes as a collective occurrence tied in with larger issues of powerlessness. Lifestyle is regarded as having an impact on the occurrence of diabetes but mainly to the extent that it triggers or exacerbates what is already inherently a quality of Native bodies. These qualities were expressed by Dorothy, a young woman from Whitefish River:

“But I think just in terms of just our lifestyle and our diet, I think even studies of the Inuit people who just ate raw fish basically in the Arctic, and then they didn’t have that lifestyle or that traditional way of food gathering, and they went into processed foods like cheese, macaroni, like a lot of pasta kind of dishes too. All of a sudden their body metabolism is introduced to this new foreign dish so to speak. And I think that’s what happened to us essentially, but I think they’re a better example even more recently in terms of contact, that kind of thing. I just think our body metabolism is a little bit *different* than non-native people. If we had been introduced to that kind of food even longer ago, maybe we wouldn’t, you know the effects over let’s say 50 years, wouldn’t be as horrendous maybe. I don’t know.” (emphasis mine)

Characteristics of the contemporary lifestyle directly responsible for its effect on Aboriginal bodies will be outlined in the following section.

Dietary Change

When discussing the impact of the contemporary lifestyle, dietary change was mentioned as causative by 23 individuals. Nonetheless, the emphasis placed on dietary change as a cause of diabetes was less than the emphasis placed on genetics in the actual text of the interviews. There appear to be no distinctions between individuals who have diabetes and those who do not. Similarly to the narratives surrounding genetics, the dietary narratives also emphasize diabetes as a collective issue rather than an individual problem. These narratives are focused on the concept of change. In this sense the process of change can be considered in line with Aristotle’s explanation of the efficient cause.

Dietary change is often discussed in the context of other changes in the lifestyle of First Nation’s People. Doris, from Whitefish River, placed the occurrence of diabetes into historical perspective:

“I know diabetes is high here compared to the other First Nations. I don’t know if it’s because we have closer access to process foods. I don’t know, that could be it. People are not into traditional foods. You know we don’t hunt as we used to. There’s only a few families that do and they just share it. I guess it’s re-learning, especially the next generation, re-learning how to prepare those foods.”

In this statement, diabetes as a recent phenomenon is directly attributable to changes from past to present. Cyndy had a similar perspective:

“Well then again it’s probably, we don’t eat the same way we did 30, 40 years ago. I can remember my grandmother cooking things like corn soup and not necessarily everything fried. So I think we’ve come into the western world of eating. We still eat our native things, but we cook them differently now. I would think that’s the reason.”

Margaret, an elder from Whitefish River, specifically explained how these ‘Western foods’ are causing diabetes:

“You eat too many of those things and your sugar builds up and there’s no place to go and it spills into you.”

The general effects of this external environment, characterized by the concept of change, are viewed as having direct effects on the internal body. Eugene discussed these effects:

“I don’t know. I’m starting to think that maybe this diet plays a big part in your body-the general chemistry, the functioning of your body. Just because you have a layer of skin separating you from your environment doesn’t mean that you’re not immersed in your environment totally and what’s put into your body has an effect.”

In this statement diabetes becomes the consequence of a bridge between an external environment based on ‘change’ and the internal body. A discussion of diabetes as a

recent phenomenon led many individuals to relate dietary habits to their larger social context. Evelyn, from Whitefish River, explained it as follows:

“Why did it show up 14 years ago? The age group that it has hit has been those that came through, that survived the drug and alcohol stages. The poor eating habits which again stems from the abuses that they’ve had.”

In this statement, both poor eating habits and the corresponding occurrence of diabetes are directly related to characteristics in the socio-political environment. This environment is further characterized as abusive. Thus through the experience of abuse that is relating the socio-political context is linked to the body and expressed in the form of diabetes. Margaret had a similar explanation:

“Hmm. Yes it has a lot to do with the change in diet it has. And I think the worst part of it is why people are overeating and not looking after themselves is again lack of employment, lack of services, housing.”

What is most noticeable about these statements is that once again, the occurrence of diabetes is identified as a collective problem. That is, rather than assign individual blame for poor lifestyle practices and the onset of illness, the lifestyle choices of native people are related to macro-political forces. This is not, however, to say that the consequences of these lifestyle practices are entirely distanced from the individual. As was poignantly articulated by Doris, whose son has been diagnosed with diabetes, there is also a recognition of individual agency and thus responsibility for the other’s illness experience:

“You know what happened. I opened a can of pop, I was in this room, and he was kind of awake. He was awake, he was just getting up, but I had a can of pop and I opened it. And you know what he did. He started getting anxious and excited. Soon as I opened it, I guess it’s that shhh sound. I

said how amazing that is. This is only a 4 month old baby and that's the reaction I'm getting. And then it wasn't until he was diagnosed at 14 I thought of that. I said I may have been responsible for that part."

Chemicals and Pollution

Enmeshed in this discourse surrounding *change* was a perception on the part of 10 of the respondents that chemicals and pollution were contributing to the occurrence of diabetes. Only one individual without diabetes mentioned chemicals and pollution as causative.

Bernard, from Whitefish River, discussed current changes to the environment:

"We've got air pollution now. Everywhere I guess. Like the water used to be clear and fresh around here; it's not anymore."

Jesse shared Bernard's perspective and discussed the impact of this pollution on health:

"A lot of people, the way they probably eat causes [diabetes]. I wouldn't trust eating fish from the lake now myself. What do they call that water? Pollution."

Raymond, from Whitefish River, re-iterated this theme:

"Well it's the food they eat. A long time ago there was wild meat, but now we eat food that is treated. They give animals certain things, I don't know, like chemicals and that's what we eat."

Distinguishing this discussion from that on dietary change, within these statements it is not the substance of the food – specifically, the amount of sugar- but rather chemicals that remain hidden in the food that are causing diabetes. In this sense, it is an insidious characteristic of the food that triggers the emergence of diabetes. This pollution is described by Dennis as having particular effects on Native people:

“There’s chemicals in the meat. You go into the store ... the meat is already chemical. Your potatoes are chemical. Your vegetables are chemical. What are you going to do? You feed your rabbit that, your tame rabbit that, he’d get sick. Yea, it’s the food. What’s in the food and what you eat, and somehow or another some people can’t overcome the diabetes. But it’s mostly native people.”

Stress

Stress was identified as causative by 14 of those interviewed. Additionally, stress was most often emphasized by individuals who also discussed genetics as causative.

Stress is discussed in the context of individual lifestyle factors: specifically, that people with stressful lives tend to have poor lifestyle habits. Nonetheless, the discussion of stress as causative is not limited to its influence on lifestyle. Indeed, in the story told by Bernard in Sucker Creek, stress is explicitly identified as a cause:

“Ok. Well I’ll tell you a little story that was told to me. There’s this old couple, 75, 76-years-old, going for a check-up every 6 months, and they are just as healthy as could be. No problems for the 6 months. All of a sudden, both of them with diabetes. The next 6 months the doctor found diabetes in them. He couldn’t figure out. He went back and checked what they ate and what ... they were eating properly, nothing wrong. So finally he just asked them. Anything happen in your family? They had lost a grandchild in a car accident. So knowing that, that’s what triggered it I guess. Maybe it had been going on for awhile, but this thing triggered it. Both of them had it at the same time. That’s what I was told and they said that stress is about the worst thing for diabetes. And there’s a lot of it for native people. Like I said, being out of a job and not having enough money. This sort of thing causes stress.”

Similar to early descriptions, in this story diabetes is already present in the individual, and that a particular event – related to stress, cultural change, chemicals and pollution in the environment, or dietary change – “triggers” its onset.

The mechanism through which stress affects the body is outlined by Doris:

“We don’t learn how to trust and how to feel. So when you don’t release all that stuff out, it stays in there and it just builds and builds and builds. Like I have heard an elder that made me think about it, he said something that made a connection to arthritis—that is a lot of anger built up. And I’m going, now why would that person say that. It takes time to be a diabetic I guess. But I don’t know. For native people it’s a high number after 40”

The length of time required to become diabetic points to the slow process linking stress with its bodily manifestation in the form of diabetes. Evelyn discussed how stress becomes manifest in the body:

“Your body gets quite eaten up too. Unless you find ways of handling your stress.”

Individual Responsibility: Revisiting the Efficient Cause

Each of the above causative factors identified diabetes as a collective phenomenon, having a particular effect on Native people, and having its roots in the larger socio-political context. Nonetheless, in the community narratives there were also descriptions relating the cause of diabetes to individual responsibility. What is notable is that these perceptions –which can be considered in line with biomedical perceptions – were emphasized to a lesser degree than the previous causative factors. Eugene discussed this perspective:

“But then there's a little bit of a factor that puts some of the blame on you and wonder, gee maybe if I wouldn't have drank so much-I was going to say party-if I hadn't drank so much when I was young, if I would have contributed to my state.”

This perspective was also evident among those who identified obesity as a causative factor. Body weight was mentioned by 8 of the respondents as a potential cause of diabetes. The relationship between body weight and diabetes was most emphasized by individuals who had been diagnosed with diabetes. For this reason I would argue that the perception of obesity as a causative factor is, in part, linked to interactions with biomedical practitioners who strongly emphasize obesity as causative. Violet, from Whitefish River, explained the relationship between her own diagnosis and body weight:

“I don’t know. Maybe it’s just, well maybe we don’t ... maybe exercising or stuff like that. Maybe that has a lot to do with it. Our weight and stuff like that. I was way heavy a few years back. I was almost 200 lbs. So I had to go on a diet and lose some weight when I was told I was a diabetic.”

From the alternate perspective of individuals without diabetes, there was a greater perception of diabetes being a result of alcohol use. Alcohol was mentioned by 8 of the respondents. According to Mary:

“I find a lot of people that have it around here used to have an alcohol problem so I think that has a relation to it.”

Bernard also mentioned a similar perspective:

“I noticed that a lot of people that used to drink a lot of wine, a lot of them were diabetics. I was more a beer and whiskey drinker myself.”

The ‘Final’ Cause

When arranged within Aristotle’s criteria for causal thinking, the onset of diabetes is explained by community members in the following manner. Descriptions by community members of a genetically pre-disposed Native body, is in line with Aristotle’s

formal cause in the sense that this body is the essence behind the occurrence of diabetes. The material cause – the matter or substrate – is defined by community members as the contemporary lifestyle. This lifestyle is characterized as *different* from past lifestyles through its influence on diet, stress, alcohol use, and obesity. The efficient cause – the source of motion – is the process of *change* that has been externally imposed on Aboriginal bodies. This process of change involves the transition from the traditional lifestyle to a Western lifestyle. In contrast, within the biomedical narratives there is an exclusive focus on the ‘efficient cause’ – where individual lifestyle practices are considered to be the cause of diabetes.

Remaining unspecified thus far, is the concept of the ‘final cause’. The final cause refers to “the way an individual event fits into some divine cosmic order” (Hage and Meeker 1988, 3). This cause is distinctly lacking in the biomedical framework, however does surface in community narratives. In an interview with Donald, diabetes was described in the following terms:

“It has a purpose that’s why we have diabetes. I guess everything has a meaning, people, sicknesses, diseases. You know, you can’t explain but it has a purpose. We’re brought closer together when we have problems you know.”

In this statement, Donald describes diabetes as having a larger ‘purpose’. This purpose goes beyond his own experience as an individual with diabetes and rather defines diabetes as a problem that is having a collective impact on Aboriginal people. According to Donald diabetes has teleological implications – specifically, the occurrence of diabetes is helping to ‘bring’ the community together.

The use of Aristotle's criteria of causation has been a useful framework to approach this discussion. I would argue that approaching causation in a wider sense than is understood within the concept of the 'efficient cause' is necessary to highlight 'what is at stake' in the illness experience. Bridging the socio-political environment with the narratives surrounding causative factors delineates the moral implications underlying definitions for the 'problem' of diabetes. In other words, an expansion of causal thinking beyond a biomedical framework is necessary to understand how people negotiate meaning and re-establish order following the onset of a chronic illness. Additionally, these understandings are important as they form the foundation for future practices surrounding health. In this sense, expanding categories of causation has both practical and theoretical implications.

The identification of diabetes as a disease having particular effects on native bodies under specific socio-political circumstances challenges the 'self' of health promotion that we dealt with in the last chapter. That is, there is a resistance against the perception of health as being within an individual's capacity to achieve, regardless of context. Rather than define a 'self' that does not fulfill its *duty* to pursue health through lifestyle practices, the 'self' articulated by these narratives distinguishes Native from non-Native bodies and illuminates the differing socio-political circumstances that affect the lived experience of these bodies. In a sense, the biomedical perception of cause can be considered a direct assault on the 'self' to which an identification of genetics as cause by community members simultaneously asserts identity and disavows responsibility.

Both biomedical and community perceptions of cause have moral underpinnings that influence possible solutions. Within community member's frameworks for understanding, solutions to diabetes that function according to biomedicine's definition of the 'efficient cause' are inadequate. An appropriate response, according to community members, is context specific and thus delves into a broader framework for solutions. The following section will explore what community members described as potential solutions to diabetes.

Negotiating Solutions: Denying Causes?

Among the respondents, 17 mentioned a preference to use traditional medicine over biomedicine. The majority of these respondents (11) are individuals who have diabetes. When faced with an illness to which biomedicine has no cure, a focus on traditional medicine effectively provides hope where there appeared to be none. Additionally, I would argue that due to the experience of diabetes as a recent disease that has resulted from processes of 'change', that a focus on traditional medicine is not only pragmatically, but also symbolically important to finding solutions. In other words, the use of traditional medicine addresses the teleological implications of the illness experience –Aristotle's final cause.

Perceptions of cause are intimately related to potential solutions and thus narratives implicating the process of *change* in causation represents the delegitimation of the knowledge and experience of Aboriginal peoples – materially expressed in the

occurrence of diabetes. Therefore a focus on traditional medicine is part of the larger process “looking back” for effective solutions – a form of relegitimation. This position was evident when Margaret discussed the different mechanisms through which biomedicine and traditional medicine work:

“Western medicine, it said that they take the best part of the herbs and things to produce what they manufacture. They take out in order to get at what they’re supposed to be using. But the Indian medicine you get everything. It works not just for one thing, like say high blood pressure. There’s medicines for that, but it also looks after some other part of your body that has to do with *why* you have high blood pressure.” (emphasis mine)

In this sense, biomedicine isolated and decontextualized whereas traditional medicine addressed the teleological elements of the illness experience – the reasons *why* an individual is ill. In this sense, traditional medicine functions beyond the ‘efficient cause’ of the biomedical narratives. As a result of these differences, many of the respondents considered traditional medicine more effective than biomedicine. Annie discussed this perspective and laments not having her grandmothers around to help her deal with diabetes:

“My grandmothers would sure put their heads together to find a way to help me with this problem. Because once when I was a baby, I vaguely remember, my mother took me to Little Current Hospital and she brought me home. The doctor said let her go die at home. She didn’t tell me till much later. Years later. Ok. So I remember lying on my grandmother’s table and she was giving me something to drink. I must have been, I don’t know, 3, 4. Around that age. And it was my grandmother that brought me back to life I suppose. I had lots of trouble I guess whatever it stemmed from whatever, I just remember my mother telling me. I remember bits and pieces of what was I doing on my grandmother’s table. I wasn’t moving. And I just remembered her lifting my head and giving me something to drink. I knew she was there. I could sense my grandmother

being by my side all the time. So mother told me much years later that if it wasn't for your grandmother, you wouldn't be here. And I said, was that what it was about. Because the doctor told me to bring you home and you could die at home here. Apparently, but it was my grandmother that done that. She was big on that stuff."

This passage describes a situation where biomedicine was unable to respond to the illness and where the use of traditional medicine effectively saved a life. The two endpoints in this story are obvious: that is, the biomedical response would have resulted in death, whereas the traditional response resulted in life. Considering traditional medicine as more effective relegitimizes the knowledge and experience of the past in light of the present occurrence of diabetes. Currently Annie faces a similar situation, yet this time without her grandmothers to help find a solution.

Further highlighting the political implications surrounding the use of traditional medicine as opposed to biomedicine several of the Elders mentioned that there are problems associated with combining these two forms of medicine. Margaret stated:

"Some people say you can't do both. Some people say if you're taking the traditional medicine then you shouldn't be taking the other. Because they fight. So I don't know."

Dennis had a similar perspective:

"What I found out about the western medicine and they have, you can't mix them both. Either that, or them medicines will fight together. You've either got to leave one, whatever. But you can't mix them."

In this sense, these two forms of medicine are considered incommensurable – and thus the choice to use either one is pending on a belief in their effectiveness. I would argue, that this choice represents an act of faith, and that the implications of this choice can be

related to the underlying moral implications for actions surrounding health. Within the moral context that emerges from community narratives – what I have termed the foundational myth - solutions reside in a return to culturally based knowledge and identity. Nonetheless, underlying such choices remains the reality of being an individual with diabetes, and a corresponding need to prevent complications. Knowledge of the biomedical position - stating that intensive treatment will prevent complications - makes such an either/or choice between traditional medicine and biomedicine untenable.

The response of community members to biomedical action can also be configured in moral terms. In other words, responses of community members are reactions to the moral position presented in the biomedical framework – what has been equated with the morality play. For Gregory, doctors were useful for pointing out what he did to promote his own sickness:

“Yea, they can help you. They say, well ok, just what have you done wrong, what did you do? And then they say, well ok, then they tell you what you’ve done wrong and so listen don’t do this too many times because you’re going to end up really sick. So it’s things like that that.”

In this sense, biomedicine has helped to define Gregory’s fall from grace. A perception that biomedicine is useful only to the extent that it identifies where an individual has erred in their lifestyle practices led others, such as Rose, to express a certain annoyance with the advice given:

“The same thing over and over again. What you’re not supposed to eat. What you’re supposed to eat.”

In this sense, the advice given is perceived as pastoral and authoritative. In the case of diabetes, this advice corresponds to a framework for action that does not correspond with the causal framework proposed by community members. That is, it outlines the tension between biomedical and community definitions of moral action – where biomedical narratives focused on individual redemption, and community narratives on a collective return to a state of purity.

The tension over the moral course of action to be taken surrounding diabetes contributes to a level of distrust towards health care providers. David explained:

“No, they’re really respectful. But there’s one doctor, he’s always trying to get a hold of stuff. I don’t know what his motive is. He wants it. Maybe he’s sincere, but I don’t know. So nobody gives it to him. It’s really hard to trust non-natives.”

This lack of trust, coupled with the consequences of living with a chronic illness, highlight perceived differences in power and authority. This perspective is evident in Annie’s statement:

“Because I’m scared. You don’t know what they’re going to do. Like you have a sore arm, you get an operation for gall stones. [laughter] That’s my version of it. For an Indian they would just say, well you’re you know or take these pills and come back and see me next week. ...I’m not a guinea pig....Like he says if it doesn’t work, come back and see me in 2 weeks. Well they say here’s some rat poison, if it doesn’t kill you, you’re lucky.[laughter] He said to me you have to take low cal sweetener, and that’s the god awful thing you’ve got to get used to. So I said to the doctor, I says, it was proven that it killed rats. So he says, what are you telling me, you’re a rat now. Because I read it somewhere when he told me I went gung ho on the thing. And it killed rats and whatever this low cal thing. So I said to him, is there an alternative. I tried to talk to him for him to talk to me on a one-on-one basis because I’m not smart, I’m not a doctor, I’m not a lawyer. I’m not an imbecile. I can understand the Indian and the English ...But I says, I read in the brochure that kills rats. Brrr.

So you're not a rat. It won't kill you. But that's chemical taken into my system. I'm still not ... I have to eat it mind you. But what's wrong with a little bit of honey as opposed to ... I keep honey because I'm like, well whatever is in there it's like ... But I've created my own sort of myself experimenting here, get away from sugar.

Power and authority is articulated over contesting definitions of health. Knowledge that Annie has gained elsewhere is deemed nonsensical according to the doctor. Within this statement, Annie asserts her own knowledge base despite a recognition of her lack of expertise. Experience challenges expert knowledge in this context and although within the situation described Annie is unable to discuss other options – she has chosen to go another route and do her own experimenting.

In sum, perceptions of causal factors are enmeshed in the struggle over the power to define what a 'moral' course of action is. This action is intimately related to general conceptions of health – conceptions which diverge between community members and biomedical practitioners. Thus, corresponding solutions for diabetes also diverge between community members and biomedical practitioners. The use of Aristotle's criteria for causal thinking has served to highlight the different levels through which causation is constructed within scientific discourse and everyday life. These constructions have led to two incommensurable courses of moral action – one involving *individual* redemption and the other a *collective* return to Eden. The following chapter will expand this discussion to explore the power represented in struggles over definitions of illness.

Chapter 5: Resistance

“If after grasping “my” consciousness in its absolute interiority and by a series of reflexive acts, I then seek to unite it with a certain living object composed of a nervous system, a brain, glands, digestive, respiratory, and circulatory organs...then I am going to encounter insurmountable difficulties. But these difficulties all stem from the fact that I try to unite my consciousness not with my body but with the body of others....In fact the body which I have just described is not my body such as it is for me.” (Sartre 1956, 401)

In this passage, Sartre describes the difficulties encountered when trying to unite his ‘body’ with the objective body of medicine. Bridging official knowledge with experiential knowledge of the body is described by Sartre as an “insurmountable” task. It is the tension resulting from this interplay - between the universal body of biomedical discourse and the lived body - that will be the focus of this chapter. Focusing on lay perceptions of the body contests the *objective* knowledge of the body that is reflected in biomedical practice and transforming the body into the *subject* of culture (Csordas 1990, 5). This transformation creates a space for definitions emerging from the lifeworld to contest biomedical definitions – and it will be argued that this struggle represents a form of resistance.

Resistance is described in two contexts within the chapter. Firstly, there is resistance to the universal body of biomedical discourse. This resistance is expressed in community narratives that describe a ‘Native body’ that is genetically distinct. Additional resistance is evident in narratives surrounding health and body size. Community narratives contest the universal thin/healthy body of biomedicine through descriptions of healthy bodies that are larger. Secondly, resistance is expressed by some

community members to an essential 'Native body'. These individuals did not share the belief that Native bodies are genetically distinct and the corresponding implication – that this difference is resulting in diabetes.

In order to frame this discussion of resistance it is necessary to first consider scientific approaches to the body.

1: Body(s)

The Universal Body

Biomedicine has compartmentalized the body and defined it as a corporeal entity, to be identified anatomically (Illich 1992, 230). Within this dominant scientific model, approaches to the body use objectivity, emphasizing measurement and classification, as the ideological tool of analysis. Good (1994, 72) describes this objectification through the intimacy that first year medical students develop with the human body in their studies, where the (dead) body becomes the object of 'skilled' manipulation in the process of learning to think 'anatomically' - a central component of the medical gaze. In effect, basic science develops an intimacy with the body in terms of *structure, processes* and *products*. Thus within these scientific stories, the subjective experience is bypassed in discussions of a 'universal' body (Lock 1993, 22).

Health is manifest in this universal body and this body is, by implication, a 'normal' body. An unhealthy body can thus be considered an abnormal body. When configured in moral terms, this sick body is concomitantly a deviant body (see Chapter 3

& 4). Foucault (1990, 140) argues that exerting control of the sick body – what he has termed ‘biopower’ - was essential for the expansion of capitalism. This control was exerted at two levels: the disciplining of bodies; and the manipulation of populations through the use of the survey. In this sense, illness renders the body visible (Becker 1995, 31) justifying interventions to permeate its boundaries (Lock and Kaufert 1998, 5). Nonetheless, through the responses of community members the universal body of medical discourse has been redefined. In other words, a focus on lay perceptions of the body can be considered a struggle against the range of interventions supported by biomedical definitions.⁸

Two central claims structure the possibility for resistance. The first claim is that:

“Where there is power, there is a resistance, or rather consequently, this resistance is never in a position of exteriority in relation to power.”
(Foucault 1990, 95)

Lila Abu-Lughod (1990, 42) in her criticism of the eagerness of other anthropologists to romanticize their portrayals of the resistance of subjugated people, has inverted Foucault’s statement to read:

“Where there is resistance, there is power.”

⁸ Understanding this struggle requires a view of power as relational rather than possessed. According to Foucault (1988, 12) these relations are “changeable, reversible, and unstable” – thus creating a space for resistance. Within these relations “there must be on both sides a certain form of liberty” – although in certain situations these relations are asymmetrical (implying domination) and the “margin of liberty is extremely limited” (Foucault 1988, 12).

With this emphasis, resistance can be understood in part as the responses of individuals to their lived reality, but also as a commentary on the networks of power influencing these lived realities. Foucault's (1990, 96) second claim articulates that:

“We're never trapped by power: it's always possible to modify its hold, in determined conditions and following a precise strategy.”

In this sense, the social field is comprised of multiple interactions of power, structured along various axes (i.e. class, gender, race). The subject in this field is constituted by these positions (Butler 1992, 41) - positions that are not merely theoretical but are based in material practices. In practical terms, this type of resistance is not necessarily manifest in overtly rebellious acts, but rather through 'everyday acts' of resistance that are more subtly expressed (Scott, 1985). Therefore, with specific reference to health, resistance is characterized by contesting: definitions of the problem; the norms dictating how one should behave; and the official discourse and documentation surrounding what has happened (Kleinman 1994, 174). These responses can also be considered a form of non-compliance (see Emke, 1993). This chapter will discuss resistance in relation to the dynamic between official and unofficial definitions of the body.

Towards this goal the chapter will be divided into two sections. The first section will explore how community narratives surrounding causal factors delineate a universal 'Native' body. This section will also explore resistance expressed in the Native challenge to this body. The second section will explore the different perceptions of body size and health emerging from biomedical and community narratives. This discussion is particularly relevant in the context of NIDDM where obesity is emphasized as a risk

factor. By exploring the different definitions for the body emerging from the lifeworld and the system, a foundation is created to embark on a discussion of ‘resistance’.

The ‘Native Body’

Through the emphasis on genetics in causation (see Chapter 4) diabetes has been defined as having specific effects on Aboriginal people. These effects are linked to a discussion of ‘difference’ and define a Native body that is genetically distinct. This distinctiveness is shaped by the concept of the ‘foundational myth’ described in the previous chapter - identifying Aboriginal people with a pre-contact state of purity and health.

Defining diabetes as a ‘specifically Native problem’ was evident in community narratives, where 20 individuals stated that diabetes is affecting the Native population at a higher rate than it is affecting non-Native populations. According to Emily:

“I read that the diabetes is mostly on to natives. Natives are the ones that usually have high diabetes compared to others.”

Eugene related diabetes to the general occurrence of disease:

“From as long as I can remember there has been a conventional wisdom that natives are predisposed to diabetes. You’re susceptible to tuberculosis and apt to develop diabetes. History will support that. Look at when the Europeans came the arrow of disease went our way. It might be a different world today had the arrow of disease gone the other way. But it did and demoralized people. When you see half your people, most of your people die, your leaders, your strongest men, and the few people who could survive were ill. It was not difficult to conquer the nation and

for us to lose a lot of tradition. So if it had gone the other way it would be different. I wouldn't say it would be better. So that's a big story to tell.”

In this statement, Aboriginal people are defined as different due to their genetic composition and therefore particularly susceptible to certain diseases that were a result of contact with Europeans. The arrival of the Europeans led to an increased disease burden among Native people in comparison with non-Native populations (Waldram et al., 1995) – a phenomenon that Eugene has described as “the arrow of disease” being directed towards Aboriginal people. In this sense, events in the socio-political and historic environment have had a detrimental impact on Aboriginal bodies.

Descriptions of Native bodies were often outlined in terms of biological differences, specifically differences between Native and non-Native bodies. Gloria described these differences:

“From what I understand from what I’ve been told as a young girl growing up and going into her adult year, we have a different makeup compared to other nationalities. Even our psychological makeup is different to understand things. That’s how we were just made. That comes from our original teachings. We weren’t made to ingest pop or things like that. But that’s how we were, we weren’t like that. And I think our bodies are retaliating. In one way it’s saying that this isn’t good for you, you got to go back to, at least try and go back a little bit to eating more the natural foods that were given to you in your original instructions. I think anyway. Diabetes is running so rapid on the reserves. Our diabetic rate here is very high... like I said we have a different genetic makeup than other people. You hear that with not only diabetes, but with other things you know like well native people can do this. They can withstand this much pain or they have a different understanding of this and that’s because we’re different. We’re not the same as other people. Just like people from India may be *different* in one way or whatever.” (emphasis mine)

In this statement, the knowledge that defines Native bodies as different emerges from ‘original teachings’ and thus the power to define the Native body involves ‘looking back’ towards traditional knowledge. In other words, definitions of the body can be considered an assertion of identity. This knowledge describes Native bodies as *different* and characterized by an ability to ‘withstand pain’. Additionally, Native bodies are defined in relation to the environment in which they were traditionally accustomed – grounding these differences in the foundational myth. Native bodies, in this sense, are described as being accustomed to eating “natural” foods as opposed to Western foods such as “pop” linking them to a past way of life described as ‘natural’ and differentiated from contemporary life - which is by implication considered unnatural. In addition, Native bodies are “retaliating” for this transition – that is, they are resisting this transition in the form of disease. Rachel re-iterated this perspective:

“How their body is made, it is not made to eat all this kind of stuff. All these, I don’t know what kind of food you’d call it, European. When they were introduced to that kind of food, their body goes through a change to adapt to that type of food, and once you adapt, I guess, years ago there was, I never heard of anybody when I was growing up talking about being a diabetic or so and so down the road is diabetic.”

Within this statement, Rachel directly linked the impact of Western foods on Native bodies to an increased incidence of disease. The identification of Native bodies with a ‘natural’ state – referring to the living conditions pre-contact with Europeans - was further emphasized by Gregory:

“Because they did have a show on TV one time on diabetes why it was so prominent in native communities. The body of a native person was more

accustomed to eating natural stuff. Whereas non-native has a different body, eating other, different stuff.”

Within these statements there is a conspicuous use of words originating in biomedical discourse such as “genetics” and “gene pool”. According to Gloria:

“Well I think, getting back to some of the outside factors like the diet and how active you are, but I think it’s in the *gene pool*. You’re born with it. Just like any other disease, in terms of the medical history in your family, some people are just more prone to certain diseases than others. For sure that’s where it comes from. But I mean there’s those extenuating factors too that play a big role in making it worse than it ought to be maybe.... Yea. Even though it’s ... I really believe it’s part of your *gene pool* or history in terms of family.” (emphasis mine)

Annie from Whitefish River stated:

“What do I think causes diabetes? Well for the better part of my life I maintained my health. I watched my diet but I got it somewhere along the line. *Genetic*. I would think it would be.”(emphasis mine)

Within both of these statements, the use of a biomedical term offers a framework to understand and validate experience. A discussion of genetics in causation illuminates what Harding (1997, 145) describes as one of the weaknesses of critiques of medicalization. Specifically, that these critiques fail to appreciate the extent to which biomedical understandings permeate contemporary discourse on the body and provide the main framework through which bodies become culturally intelligible.

Despite the use of biomedical terms, definitions of the body provided by community members challenge the biomedical premise that knowledge will empower individuals to pursue health through lifestyle practices. It is evident that the logic that increased knowledge will affect behaviour is false through the realization that this

knowledge also contributes to an awareness of the lack of unanimity in professional thinking. In the case of diabetes, where etiology is multifactorial and a simple cause/effect relationship does not exist these “fissures in medical expertise provide opportunities for [individuals] to rely on experiential knowledge to resist authority” (Abel and Browner 1998, 322). In this sense, naturalizing the occurrence of diabetes for certain individuals helps to maintain a critical distance from biomedical authority. Therefore, biomedical knowledge is appropriated, and reframed in definitions of the universal ‘Native body’ in order to assert control over the occurrence of diabetes.

Through their identification of cause, individuals actively choose how to respond. The investment of power in the body, through medical definitions, also invests the body with the power to resist these definitions (Foucault 1990, 137). Rather than consider the emphasis on genetics in causation as representing a lack of control, one could argue that within these contexts it asserts individual control in light of the significant lifestyle interventions deemed necessary to prevent diabetes. A perception of genetics as cause implies that the disease is *not* preventable and therefore no changes in lifestyle are required. When asked about prevention, Emily stated:

“I don't think so because once they say it's hereditary, it's hereditary. It runs in the family.”

Mary, a young woman who does not have diabetes, discussed her attitude towards prevention:

“If you take care of yourself? Isn't this supposed to be like a hereditary issue? So I don't know if you can really prevent heredity, unless you play with your genes, I don't know.”

Naturalizing the occurrence of diabetes for *certain* bodies – in this case, the ‘Native body’ -releases them from further biomedical interventions. As such, definitions of the body, and identification with the universal ‘Native’ body can be considered expressions of agency and as part of the larger struggle against the ‘universal’ body of biomedical discourse.

In sum, a discussion of the impact of diabetes on Aboriginal people has led community members to distinguish between Native and non-Native bodies. Native bodies are described as genetically and psychologically different. These distinctions also relate to the different environments in which these bodies have originated. In other words, diabetes is attributed to the impact of change on Native bodies –linking these bodies to a past state of purity and health. In this sense, their contemporary state of illness can be considered a critique of the society in which they now live and thus through the occurrence of diabetes these bodies are “retaliating” for being exposed to this lifestyle – considered to be ‘unnatural’. This view, that the Native body is intimately linked with ‘nature’ and that disease is a reflection of the ‘unnatural’ environment in which these bodies now live displaces the universal body of biomedical discourse - whereby sickness results from irresponsible behaviour.

Native Body(s)

Not all community members distinguished Native bodies in terms of genetic composition. Although the majority of respondents identified a ‘higher’ occurrence of diabetes among Aboriginal people, 7 individuals strongly opposed this position. These

narratives displace some of the previous ‘common-sense’ assumptions and highlight the potential implications of defining the Native body in essentialist terms. In this sense, these narratives indicate that cultures are not homogeneous and that perceptions *within* cultural groups are also fractured. In Hegelian terms, these narratives highlight how everywhere in the social world we find the process of unfolding (Lacey 1996, 145). In this framework, the social world develops dialectically through the interplay of opposites.

Rather than define the Native body as able to ‘withstand pain’ and closely associated with ‘nature’, these narratives express a resistance to certain consequences of this definition. These consequences I would argue emerge from the relationship of the ‘Native body’ to illness within the contemporary socio-political landscape. The following dialogue with Jesse outlined this position:

Jesse: “But I don’t mean native people. A lot of people. If you went through the communities on the island, you’d see a lot of non-natives with diabetes.”

Interviewer: “So you don’t see it as a specifically native problem?”

Jesse: “Not only natives. Everybody. You just can’t say, all the native population is the worst off for diabetes. If you probably did the whole study in Canada, you’d see that...It’s not just native. It’s everybody. It’s in your genes or whatever. It’s just sitting there waiting for it to come out.”

Within this statement, both Native and non-Native individuals are defined as equally susceptible to diabetes. Additionally, although the cause of diabetes is still considered to be genetic, Jesse’s statement implies that there is no genetic distinction between Native

and non-Native bodies. Therefore, diabetes is equally present in both Native and non-Native genes.

The perspective that there is no distinction between Native and non-Native bodies highlight the differential impact of power on the 'Native body'. Eugene described this power in terms of 'over-representation':

“But a lot of people I know, like when I'm at school I meet people with diabetes too, and they're not natives and they're taking the insulin. So it's a concern everywhere. Maybe it's must more predominant, just like our *over-representation* in the jails. I don't know who's fault that is. That's another ball of wax.” (emphasis mine)

In this statement, Eugene equates the over-representation of Aboriginal people in jails with an over-representation of illness among Aboriginal people. In this sense, Eugene highlights the power/knowledge that defines a group of individuals generically 'at risk' for a certain illness. Specifically, it highlights the power that defines Aboriginal people as 'criminals' or labels them as 'sick'. Eugene's reaction highlights a resistance to being identified according to essential (due to genetic makeup) and thus unquestionable characteristics.

Rose had a similar reaction when asked how she felt when people discussed a 'greater amount' of diabetes in Aboriginal communities she responded:

“That part makes me mad sometimes. Why pick on the native people. They're not the only ones that have got diabetes. I said I know a lot of white people that's got diabetes. They are more and more and more... That's what makes me angry when they say that. And I said, why the native people. There's a lot of people out there that's got diabetes. Every time you turn around somebody says they've got diabetes. Why only the native people. A lot of people have got it.”

Rose's anger at isolating the occurrence of diabetes to Native people, reveals a resistance to being labeled *different* - when difference is based on illness. Eugene also summarized the consequences of the association of Aboriginal people with an increased occurrence of diabetes:

“How does it make me feel? That's a good one. I want to pass on that question. Actually you know if I could ... that makes me feel kind of mad and it kind of makes me feel like not as good. You know what I'm saying? Like you can't hack it, you know. So I said it. It makes me feel maybe inferior.”

Summary

In sum, the majority of community narratives have identified Native bodies in essentialist terms. These narratives link the 'Native body' to the foundational myth - where the contemporary occurrence of diabetes can be considered a form of resistance to a contemporary socio-political context defined as 'unnatural'. Thus these narratives resist biomedical definitions describing the sick body as 'unnatural' and in contrast emphasize that it is the sociopolitical environment that is 'unnatural'. According to biomedical definitions, the 'Native body' is linked to illness. Nonetheless, when conceived within Aboriginal frameworks for health this same body can be considered healthy as it is asserting its cultural identity. Thus, the 'Native body' links the individual to a category that is biomedically sick but socially resilient.

2: The Appearance of Health

Thus far definitions of the body emerging from community narratives have focused on difference in the form of genetic makeup. At this point, the discussion will shift towards the physical appearance of health according to both community members and health care practitioners. Outlining divergent perceptions of the physical appearance of health describes how bodies are marked or inscribed in terms that are visible. Considering the relationship between body size and health materially grounds this discussion. According to biomedical frameworks disease resides in the physical body and in the case of diabetes, the appearance of this body as 'obese' forms the rationale for medical interventions. In contrast, community narratives associate diabetes with weight loss thus questioning whether a thin body is healthy.

The biomedical emphasis on obesity as a risk factor for diabetes creates an impetus to explore what 'health' looks like. That is, exploring different perceptions of the appearance of health on the part of community members and health care providers illuminates the contingent relationship between biology and culture. Knowledge of the body is therefore considered to be a product of history and culture, both specific and changing throughout time (Lock 1993, 39). Contrasting community definitions for 'healthy bodies' with biomedical definitions further contests the notion of the universal body. In this sense, the definition of a healthy body is contingent on overall definitions for health - be they holistic or physical. Socio-cultural attention to the construction of

bodies is therefore essential to understanding power and knowledge that defines these bodies.

According to Becker (1995, 27) core cultural values are encoded in aesthetic ideals for body shape. In the West, the ideal body shape has been normalized as the thin body and therefore caloric control, reflected in the practice of dieting, can be considered a normative behaviour (Litva and Eyles 1994, 1087). The thin and therefore healthy body is a disciplined one (Becker 1995, 36). In this sense, obesity becomes a sign of deviance and thinness a sign of virtue. Nonetheless, ideal body shapes have changed throughout Western history and therefore it is not surprising that there exists cross-cultural variability in aesthetic ideals for body shape and weight. Becker (1995, 37) found that among Fijians a larger body is considered a sign of health. Similarly, a number of studies among First Nations people in Canada have identified a relationship between a larger body size and health (see Young 1996, 1665; Marchessault 1995, 106; Boston et al. 1997, 10; Heffernan 1995, 281; Spielmann 1998, 30).

Among community members, the majority (18 individuals) articulated that a healthy body is one that is neither too thin nor too large. David stated:

“I always have a little extra just in case I’m out there somewhere and I run out for a few days. If I was totally fat free, my body would need to be constantly charging. If I have a little bit on me, say a few extra pounds over, not 20 or 50 or 100, but enough to just ... say I ran out of food and I was stuck and walking or going far, at least I’d have enough to get to somewhere else. You need a little bit to be in good health.”

For David, having a bit of excess weight is considered healthy for pragmatic reasons – specifically, a fear of running out of energy. According to Mary, a healthy body size is dependent on the individual:

“I think if you’re at a healthy weight, whatever that is, for every person it’s different, then you should be ok”.

When asked whether it’s healthier to ‘have a bit of weight on’, she responded:

“Yea, to have some meat on you.”

In the above statements there is a sense that a certain degree of body weight is both acceptable and healthy.

The following dialogue with Dorothy further discussed these differences by distinguishing between Native and non-Native perceptions of weight:

Interviewer: “Do you think weight is something that preoccupies people at all?”

Dorothy: “No.”

Interviewer: “Ok. So people don’t worry if they are overweight?”

Dorothy: “No, I don’t. I don’t think you have ... well I don’t know if this is really true, but I don’t think you have too many anorexic or bulimic Nishnaab’s cruising around. Not to say that, for any age group I think, there is some probably going down to that age like with all the pictures of Kate Moss, or trying to be like a Spice Girl or that kind of thing....But I don’t think it’s as rampant as maybe in your culture.”

In this statement Dorothy distinguished between Western images of health – as represented in popular culture – and Aboriginal perceptions. She relates Western images to the problems of anorexia and bulimia – problems that she states do not similarly affect

Aboriginal people. That is, she differentiates Native bodies from non-Native bodies by discussing perceptions of body weight.

According to the holistic definitions for health utilized by the majority of community members – the concept of ‘losing weight’ could be considered an *unhealthy* venture. Doris described this position:

“You take one part of the pie, cut it up. Everything is kind of related. See, for example, if I were to lose weight, I would have to do a lot of self talk for myself first and try and make realistic goals. First it begins with the mind. If I’m going to lose weight I’ve got to do it in a good way. What is comfortable for me. But sometimes I find when I think of diet, you take the ‘t’ it means die. To me it’s just moderation. How much you’re going to take. That’s what it boils down to. To me it would be unhealthy. I did go on a diet. I’d lost, I think I went down to 150 one time, through a dietitian. But that’s following their ... ok you’ve got to eat this, this is the amount that you’ve got to eat. And I had to really think about it. Especially with my grandmother. My grandmother taught me, said, you were born with big bones and you come from a line where there’s women with big bones, so why are you doing this?”

In this statement, losing weight at the expense of a healthy mind will not serve to maintain overall health and is therefore not worthwhile.⁹ The association of dieting with death implies that losing weight can be considered a health risk rather than benefit. Dorothy’s anecdote about her grandmother highlights a further dimension of how knowledge of the body is formed in this context. Within this statement, the process of losing weight could effectively be considered a denial of her cultural heritage - that is, her

⁹ Similarly, Litva and Eyles (1994, 1087) found that in a small town in Southern Ontario, individual behaviour, such as dieting, was only considered important if it contributed to a person “feeling good about themselves”.

relationship to other women with larger bones – relating the appearance of the body to its historical context.

Additionally , 8 individuals explicitly mentioned that they consider it unhealthy to be thin. Mary stated:

Interviewer: “Do you think the body sizes of the people we see on TV all the time

Mary: “Skinny women?”

Interviewer: “Yea. Do you think that that’s healthy?”

Mary: “No I don’t. That’s gross.”

In addition to labeling the ‘people we see on television’ as unhealthy, Mary also described these bodies as ‘gross’. In this sense, Mary described an aversion to bodies that are considered desirable within a Western context. A similar perspective is articulated by Elaine, in the following dialogue:

“I think that people that are really, really thin, I think there’s something wrong with them. It comes to my mind for some reason. And that’s why I don’t want to get really, really skinny.”

In this statement, the appearance of a thin body is considered an indicator of poor health. Wondering ‘what is wrong with them’ within the context of holistic definitions for health further implies that a thin body may be related to poor health in other realms – be it the mind, the emotions, or the spirit. Roger Spielmann (1998, 30) similarly identified that in the Ojibwe community of Pikogan that an individual with “plenty of meat on their bones” is considered healthy and strong. He attributes this attitude towards weight to the traditional living circumstances in the bush where having enough fat on the body was

essential in order to survive periods of scarcity. Thus, within the community of Pikogan the phrase “You’re so fat!” is considered a compliment.

Nonetheless, 4 individuals explicitly mentioned that they consider it unhealthy to be overweight. When asked what a healthy body size would be, Margaret stated:

“Overweight no. But then again some people think that you have to be big to be healthy. And that’s not the way it is”.

In this statement, Margaret identifies that although certain people in the community consider it healthy to be larger, this is a perception that she does not share. An additional 8 respondents mentioned that they consider it healthy to be thin.

Aboriginal Perspectives: The (Thin) Diabetic Body

Our discussion thus far has centred on perceptions of ‘healthy bodies’. As previously mentioned discussions of thin bodies led community members to question the overall state of health of those individuals within a holistic framework. In other words, the appearance of a thin body was considered an indicator of poor health. Within these narratives a number of individuals associated the onset of diabetes with weight loss, further linking the thin body to illness. This relationship was outlined by Jeannette:

“My common-law husband is a diabetic. Before that he was really fat and he became a diabetic and lost a lot of weight.”

Remaining unspecified in this statement is whether his loss of weight was a result of a change in dietary practices or whether it was a result of the disease itself.

A more direct relationship between the onset of diabetes and weight loss was described by David:

“Yea when I first found out I figured my whole body was going to alter incredibly. And I had seen people with diabetes, I guess they’re not really looking after it, but they dropped. They were heavy, fat, strong set people. They’re thin and their arms became skinny and weak. Yea into the sick, weakly, cankerous state where ...I don’t know. I was wondering would that happen to me and I don’t want it to. But in zombie movies that’s what my impression– very thin and just sunken in, skeletons.”

In this statement, David describes his fear that the onset of diabetes would ‘alter’ his body- specifically that he would become skinny and weak. Within the passage, David describes the relationship between health and illness equating “heavy” and” fat” people with strength and “thin” and “skinny” people with weakness. David clearly states that he does not want to lose weight and have his appearance transformed into a “thin, weakly, cantankerous state” like in “zombie movies”. As was present in Dorothy’s discussion of dieting, David also links weight loss to death – articulating that he did not want to become like a ‘skeleton’.

Biomedical Perspectives: The (Obese) Diabetic Body

In contrast to the perspectives of community members, discussing general ‘health’ with health care providers focused on the relationship between obesity and ‘poor health’. According to Karen:

“I think looking at obesity is a big problem in any area. I think in the [communities] there are probably more people that are grossly overweight, like more than 10, 20, 30 lbs., but more like 50 or 100. So that’s a big health problem.”

Within this statement Karen identified an elevated rate of obesity in these communities. She also emphasized that she considers this obesity to be a significant health problem.

John had a similar perspective:

“A healthy body is someone that when you look at them they don’t appear obese.”

Within John’s statement there is a direct relationship between weight and health – specifically, that obese bodies are unhealthy. William discussed the relationship between obesity and diabetes:

“An obese body is more likely to develop health problems and in populations where there is a higher degree of obesity there is definitely more health problems. And the majority of people that we have in the First Nations population who are diabetic are also obese.”

Within this statement, William re-iterates that obesity has a negative impact on health – as represented in the occurrence of diabetes. Additionally, William outlined that most First Nations people with diabetes are obese. Similarly, John perceives a direct causal relationship between obesity among First Nations people and diabetes:

“I think obesity is a factor, you see more diabetes in the Native population and you also see more obesity.”

Within these statements, the large amount of obesity observed in Aboriginal communities, defines Aboriginal bodies as predominantly obese. The relationship between poor health and obesity, by implication, further labels these bodies as abnormal. This perception informs health care interventions and is reflected in the emphasis placed on obesity as a risk factor for diabetes. Charles described the implications for this perception of weight on potential health care planning:

“I think probably one of the most important things we can teach them is weight control. You don’t see a lot of skinny diabetics.”

This statement diametrically opposes the position found in the community narratives where diabetes and general poor health were linked to a state of thinness.

Within these narratives, the cause of poor health resides in the physical realm, and therefore health care interventions should focus on the physical forms of poor health, such as obesity. These definitions contrast with those of community members who viewed health holistically and therefore identified the source of poor health to factors beyond the physical sphere. Not only were definitions for health different between community members and health care providers, but the actual ‘appearance’ of health was also different. Directly stated, within community narratives poor health was reflected in a thin body whereas biomedical narratives described poor health as a characteristic of obese bodies. Beth, along with many of the health care providers, discussed these perceived differences:

“No, I don’t think people think that around here that that little skinny toothpick kind body is good. They don’t see that image as positive. As a matter of fact, for our fitness week there we did a display on the wall there, and the girl that was sitting here she usually tries to help me out with the display board, her pictures that she put up to show people running and using different equipment and stuff, the pictures were of these really pretty thin women and I don’t know how many people pointed that out to us...” “What’s this. Look at these people. How come they’re all so thin?” And I thought that was good that they did that...It wasn’t realistic to them.”

Through this story Beth communicates that a thin body is not a positive image for community members. Additionally, Beth identifies that this image is not ‘realistic’ – that

is, it does not correspond with Native perceptions of a healthy body. Karen, also described these differences:

“It’s more acceptable to be like a good 50 or 60 lbs. overweight. I’m actually quite surprised myself...like when I look at someone and I think, oh. Like in my mind I’m sort of thinking if they lost like 20 lbs. they’d probably feel a bit healthier themselves. Because you’re carrying extra weight for your heart and everything. For your joints. And they feel comfortable at that weight. Like people that are 5’2” and weigh 160 or 170 lbs., actually I’ve heard them say to me and to other people that, no I feel good about my weight, I like this weight. I just don’t want to put any more on. Whereas, I think like ooh, you’re going to end up with problems later when you’re older and your metabolism slows down... the image is different.”

Karen articulates that the perceptions of weight on the part of community members are not what she would consider healthy. Noticing people who are overweight by her definitions leads Karen to consider the future effects of this weight – specifically, the health problems associated with obesity.

In contrast, Doris, a community member, described a thin body as unhealthy – a position diametrically opposed to Karen’s. Doris stated:

“I’ve seen skinny people and I’ve said, hmm, I don’t know is that healthy. They might be skinny but you wonder are they really happy though?”

In this statement Doris makes a direct connection between the appearance of health and an individual’s level of happiness. That is, contrary to Karen’s consideration of an unhealthy body (defined as obese), Doris focused on the emotional source of poor health as reflected in a thin body. Not only are definitions of a healthy body different, the approach taken towards achieving health is also different. Karen’s approach is most

concerned with physical dimensions of health whereas Doris' is concerned with the emotional dimensions of health.

In sum, the link between weight loss and poor health, and the corresponding aversion to a 'thin body' on the part of community members, contrasts with biomedical definitions of the 'obese body' as unhealthy. The healthy body of biomedical discourse is, in effect, displaced by community definitions thus calling into question universal concepts of what health 'looks like'.

Bodies and their Resistances

Foucault has argued (1990, 143) that when the problem of health became a question of developing techniques to maximize life, the power articulated over the body and its construction became a productive and thus tolerated force in society. Within this framework, the deployment of health was facilitated through the body and the subjugation of the body was assured through biomedical technique. Through the interaction of the historical and the biological, the body was not effaced but rather made visible through modern technologies that took *life* as their objective.¹⁰ These technologies defined a universal body, normalizing the concept of health across the social body. The pursuit of health then became contingent on these definitions.

¹⁰ Foucault (1990, 136) describes this 'right to life' as emerging from the Classical Period where the sovereign could demand his subjects to go to war in his defense. As such, power over life and death was conditioned by the defence of the sovereign and his survival. This concept has been transformed

Within the medical construction of symptoms and risk, the individual is formalized within power relations (Foucault 1979, 74). In other words, individuals have a ‘right to life’ within biomedical discourse, but also, as responsible citizens, have a corresponding duty to pursue health, within biomedical parameters.¹¹ Nonetheless, this right to life becomes dramatically redefined when read out of the context of the dominant group. This chapter has demonstrated that biomedical definitions are contested within community narratives surrounding both the definition of the ‘problem’ of diabetes, and the definition for ‘healthy bodies’. According to community narratives, the Native body has been essentialized in biological terms, and a ‘healthy’ body is described as explicitly *not* biomedical. In effect, this distinction between Native and non-Native bodies appropriates biomedical risk factors for diabetes – specifically, genetic predisposition and obesity – and dramatically alters their potential effects. That is, an emphasis on genetic causes implies that solutions to diabetes that target the individual and their lifestyle choices will be ineffectual. Additionally, contesting definitions of a healthy body contest medical interventions based on weight loss.

With specific reference to genetic predisposition, the relationship between these genetically distinct bodies and healthy conditions pre-contact explicitly defines the ‘Native body’ as the product of relations of power embedded in historical and political

in modern times to the right of the ‘social body’ to ensure, maintain, and develop its life. In other words, it is not the ‘sovereign’ but rather the ‘population’ that must be defended.

¹¹ Parsons (cited in Turner 1996, 38) referred to the situation where illness becomes a way to explain why a person cannot comply with social expectations as the ‘sick role’.

processes. Within community narratives, this body is linked to the 'natural' and therefore healthy state that existed in pre-contact times. In this sense, a socio-historical bridge is formed between the 'Native body' and contemporary change. This link between the Native body and a natural, pure state of being has particular significance when contrasted with biomedical definitions for health. The type of essentialism that the community narratives articulate strategically opposes biomedical definitions - where the 'unhealthy' body is a result of individual choices rather than factors in the socio-political environment. Therefore, community definitions contest the biomedical implication that unhealthy bodies result from deviant behaviour.

The counter-narratives emerging from community members that oppose a view the Native body in essentialist terms highlight the networks of power that constructing this body. That is, these counter-narratives indicate the 'stakes' involved in redefining the body in essentialist terms - where the physical expression of this *difference* is diabetes. Specifically, these 'stakes' refer to how accepting this definition for the 'Native body' involves identifying oneself with a body that is considered biomedically ill, and by implication, morally irresponsible. Therefore, although the construction of the 'Native body' in essentialist terms can be considered a form of resistance, it may also entangle these bodies in potentially larger and more pervasive webs of power.¹² In other

¹² Lila Abu-Lughod (1990, 52) has discussed this potential in the context of Bedouin women rebelling against their elders. In these circumstances, this rebellion is backing these women into a wider and different set of authority structures associated with Egyptian society. Thus, she cautions that "If the systems of power are multiple, then resisting at one level may catch people up at another level!". In other words, resistance may link individuals to structures that are potentially more rigid than the previous ones.

words, there are societal implications to identifying oneself as different - under circumstances where one expression of this difference is a predisposition to illness. Frustration over the sense of inferiority and weakness that results from being labeled 'sick' reveals these consequences. Nonetheless, these narratives also reveal that there are also contradictions *within* cultures and cautions against universalizing or 'romanticizing' discussions of resistance.

Resistance is further evident in Aboriginal discussions of body weight. These narratives re-theorize the biomedical emphasis on obesity as a risk factor for diabetes through different interpretations of the appearance of health. The emergent definitions for 'healthy bodies' can be considered a form of non-compliance when contrasted with official definitions for health (Emke 1993, 59). Simply stated, a thin body is regarded by the majority of community members as unhealthy - a position diametrically opposed to that of health care providers. Additionally, the association of diabetes with a weakened and thin body, clearly defines this body as undesirable. For community members, a certain amount of weight is considered healthy and therefore, a biomedical focus on the need to lose weight to achieve health becomes a narrative at odds with known cultural referents.

Knowledge about the body emerging from community narratives is directed towards negotiating solutions to the 'problem' of diabetes. That is, an emphasis on the effects of contact and change on Native bodies articulates that solutions reside, not in medical interventions, but rather in healing that addresses the social, political, and

historical circumstances that have constructed these bodies as different. Through biomedical attention to essential individualism, the body becomes evidence for the fact of difference rather than a way of exploring how difference is established. This 'established' (biological) difference sanctions relations of domination along the lines of race, class, and gender. Within community narratives, difference is not defined individually, but is rather based on a collective definition of Aboriginal people. According to Foucault (1980, 194):

“Freedom does not basically lie in discovering or being able to determine who we are but in rebelling against those ways in which we are already defined, categorized, and classified.”

In this sense, definitions of the Native body as historically and contextually specific, can be considered an expression of this freedom – where struggles over the definition of bodily boundaries become central to both domination and resistance.

Chapter 6: Conclusions

“For the dyers the one moment of superiority came in the showers at the end of the day. They stood under the hot pipes, not noticeably changing for two or three minutes – as if, like an actress unable to return to the real world from a role, they would be forever contained in that livid colour, only their brains free of it. And then the blue suddenly dropped off, the colour disrobed itself from the body, fell in one piece to their ankles, and they stepped out, in the erotica of being made free.” (Ondaatje 1994, 132).

The ‘livid’ colour marking the bodies of the dyers in this passage, is much like the official discourse surrounding diagnosis, cause, treatment, and risk that have marked the diabetic body. The interaction between official definitions for health and illness and those emerging from the lifeworld can be considered part of larger struggles over representation. As an exploratory qualitative study this thesis has focused on these definitions – specifically, Aboriginal and biomedical perceptions of non-insulin dependent diabetes mellitus. Community narratives have been involved in ‘disrobing’ these official definitions and thus definitions for the ‘problem’ of diabetes emerging from the lifeworld can be considered part of this ‘stepping out’.

This study has used social science to highlight the disparity between dominant cultural ideals about health and illness and the experiences emerging from the lifeworld. These disparities are significant when considering the impact of socially and economically structured life processes on health. Official frameworks on health do not contain the language to discuss how social, economic, and political environments create barriers in the ability of certain groups to live ‘healthy’ lives and to ‘manage’ illness. Juxtaposing biomedical narratives with the narratives emerging from the lifeworld has

highlighted these dimensions of the environment in which people *become* ill. A summary of the findings of the analytic chapters dealing with diagnosis and diabetes management, causal factors and definitions for the body will briefly revisit the environment that has been described in the narratives.¹³

Wrestling with Normality

Biomedical and community narratives centre around divergent definitions for normality. As such, the interplay between these two perspectives highlights what Becker (1997, 15) has referred to as “wrestling with normalcy”. According to official narratives, normality is equated with the absence of disease and therefore the observation that there are higher rates of diabetes among Aboriginal people describes a situation that is ‘abnormal’. In other words, biomedical frameworks challenge the ability of these communities to be ‘normal’. In contrast, ‘normality’ is redefined within community narratives so that individuals, despite the presence of diabetes, can *be* well. These terms are intimately related to general conceptions of health and therefore within the holistic framework used by community members health is achievable despite being labeled biomedically ‘sick’. Specifically, community narratives describe health in terms of cultural identity and social resilience, and thus what is considered ‘normal’ within community narratives is also conspicuously different from biomedical narratives. In this

¹³ The following discussion will consider theoretical implications of the research. Please refer to *Conclusions* Chapter 3 and the *Community Report* (Appendix 2) for practical considerations.

sense, within community narratives a tension emerges between the desire for normality and an acknowledgement of difference. The expressions of *difference* emerging from community narratives can also be considered a form of resistance (Becker 1997, 17).

Chapter three has problematized the rationale for intensive management of NIDDM by exploring the uncertainties in the clinical literature underlying this position. Nonetheless, when clinical science is translated into the need to treat diabetes *in practice* the measurement of the blood sugar level provides a tangible marker amidst the noise of scientific uncertainty. Within this framework, normality is achieved when the blood sugar level is controlled. Thus according to biomedical narratives, the diabetic ‘self’ has a duty to act responsibly and manage their diabetes – with the blood sugar level as a marker of success or failure of the ‘self’. Although within a biomedical framework, the category of ‘diabetic’ is considered stable - individual actions within its confines are morally questioned.

Community members with diabetes, however, describe a different self – specifically, a self who encounters barriers to achieving ‘normality’ according to biomedical definitions. These barriers highlight the tension between individual action and societal constraints and highlight how *certain* selves are better able to manage diabetes than others. In this sense, community narratives emphasize the social and emotional consequences of the disease. Within these narratives ‘normality’ has been redefined and it is the social rather than the physical consequences of living with diabetes that need to be redressed for normality to be achieved. Thus two divergent selves and two

divergent means of achieving normality emerge within narratives surrounding diabetes management.

Narratives surrounding causal factors also describe this struggle. Illness itself threatens normality and thus these narratives can be considered an integral response to re-establishing order and coming to terms with the loss of freedom that follows the onset of diabetes. In Chapter four, two different causal stories are outlined and underlying each a particular moral position regarding the 'righteous' pursuit of health. Biomedical narratives emphasize the role of lifestyle factors, particularly the impact of obesity, in causation. Within the chapter, the morality underlying this story of causation has been equated with the 'modern morality play' – whereby the fall from grace is followed by individual actions to redeem the self. In the case of diabetes, redemption occurs through responsible lifestyle choices. In contrast, community narratives emphasize the role of genetics. Within the chapter a parallel was drawn between this story of causation and the 'foundational myth'. These narratives describe diabetes as *collectively* affecting Aboriginal people – thus identifying those affected as *different*. The moral pursuit of health within this framework involves returning to an original state of health and purity through traditional knowledge. Within the chapter, Aristotle's criteria for causal thinking was useful in highlighting how people invoke definitions of cause that move beyond a scientific framework.

Chapter five further highlighted this struggle against official definitions by outlining the divergent definitions for the body that emerged from biomedical and

community narratives. The concept of resistance was central to this chapter and was discussed in two contexts – the resistance of the universal biomedical body by community members; and the resistance of an essentialized Native body by certain community members. Resistance to the universal body of biomedical discourse became apparent in community narratives surrounding causation and the physical appearance of health. Through a discussion of cause, Native bodies are defined as genetically and psychologically different due to the ‘natural’ environment in which these bodies originated. The perspective that these bodies are now retaliating for the contemporary living conditions, in the form of diabetes, challenges biomedical narratives that consider poor care of the self to be the main cause of diabetes. Additional resistance to the universal body of biomedical discourse surfaced in narratives describing the relationship between health and body size. These narratives challenge the biomedical position that a thin body is healthy and rather describe a healthy body that is larger. Within community narratives a relationship is described between diabetes and thinness – a position that diametrically opposes the biomedical association of diabetes with obesity. Nonetheless, resistance also existed within community narratives. Specifically, a number of individuals opposed a perception of increased diabetes among Aboriginal people. These individuals did not share the belief that Native bodies are genetically distinct, and the corresponding implication that this difference is resulting in diabetes. Resistance within community narratives lends support to a concept of society as processual and cautions against viewing cultural groups as stable and homogeneous. Divergent definitions for the body emphasize that negotiations over ‘normality’ are also expressions of resistance.

Overall, these narratives challenge the universal body of biomedical discourse and embed Native bodies in the particular socio-historical conditions in which they now live. Through the narratives of community members it is possible to consider how the “past is sedimented into the body” through the presence of diabetes (Becker 1997, 12). Final conclusions will briefly explore this link between the body and society.

The Body in Society

“At the signing of the treaty, the Indians and whites were to bury the hatchet and be friends. Mr. Wm. Robinson promised that everything would stay the same and that everyone from the oldest person to the smallest child would receive money once a year....Well they were fooled. Not many good things about the white people treating the Indians.” Anonymous Informant (Pitawanakwat et al.)

A quick glimpse at the historical relationship between Aboriginal people and ‘whites’ reveals the struggle over power and authority at its foundation – be it negotiations over land or definitions of health. The above quote was taken from an informant at the 1850 Treaty Negotiations between the ancestors of the Anishnaabe of Whitefish River and William Benjamin Robinson in Sault Ste. Marie. Upon conclusion of these negotiations the informant describes how community members were under the impression that life would effectively “stay the same”. History, as described in the narratives of community members, depicts an alternative situation – specifically, the process of change that these communities subsequently underwent. Discussing definitions for the ‘problem’ of diabetes has elucidated descriptions of this process of change and its corresponding impact on the lifeworld.

Narratives surrounding diabetes identifies the different sociopolitical environment in which these bodies are lived and forms a bridge between the individual and the collective. In this sense, bodily complaints, in the form of diabetes, evoke social complaints. David discussed the source of these complaints:

“It’s changed. A lot people ... before contact everybody lived in a good way that everybody had a job to do, position to work on, something like good hunter, good fisher, whatever. It was community-based and everybody communicated, they had a lot of talking circles and stuff like that where something was wrong we’d bring it out and get it out. Nowadays people don’t talk. They talk but no one listens. Like some people talk but they don’t communicate. And others just sit there and hear but they don’t actually listen. So it’s a big gap. They try to say stuff. They don’t get their true feelings and emotions carry all that garbage and get it out of you.”

David describes a situation characterized by powerlessness and an inability to be heard.

David’s statement highlights how dealing with diabetes is not simply a matter of increasing ‘education’ or medical services. Community narratives I would argue have transformed diabetes from a biomedical *disease*, into a *symptom* of the particular socio-historical circumstances in which Aboriginal people currently live. In this sense, the sense of powerlessness articulated by community members over their ability to prevent, treat, and manage diabetes directs discussion towards issues of social justice. In other words, it highlights how certain groups are better able to achieve health within biomedical parameters thus providing a link between biology and society. This link was stated plainly by Edna:

“Diabetes is when you can’t taste the sweetness in life – because you’re so bitter.”

When health is conceived in terms described by community members, the biomedical response to diabetes can be considered deleterious to health. In other words, the social and emotional consequences of not being able to ‘manage’ or ‘prevent’ according to biomedical definitions is significant when considered within a holistic framework. Although health may not be achievable in biomedical terms, community members articulate that health is attainable through cultural identification and revisiting the knowledge of the past. The importance of the ‘past’ becomes apparent in consideration that:

“The progress of medical science itself relies upon the subsequent discrediting of the legitimized knowledge of the past” (Emke 1993, 59).

Within community narratives there has been an emphasis placed on relegitimizing this knowledge. Within the thesis the process of relegitimizing cultural knowledge and identity has been presented as a form of resistance. The importance of “looking back” towards this knowledge was expressed by Mary:

“Everything that’s been going on in the reserve they have to go back to that healing. Most people started to try and be more aware of their culture and trying to be a part of their culture because we lost that a long time ago. I find that way the community is trying to get that back. You never would have thought of a healer coming in, and now they’re coming in talking. And all these teachers. In that way it’s you’re learning more. And they’re teaching at the school so that the kids don’t get lost.”

In this statement, ‘being lost’ is equated with being alienated from one’s culture.

According to community narratives, ‘culture’ is closely linked to the pursuit of health and therefore ‘alienation’ needs to be redressed in order for health to be achieved. Dorothy states:

“I think when you learn more about your culture, any culture, not just having to be Ojibway, you learn more about your tradition, you learn more about your culture, and I just think it heightens your whole, I don’t know, your self esteem, your proudness, and just influences your positive part of your life and your health is just going to benefit. Like it’s just this ripple effect. It’s hitting all these positives throughout.”

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APPENDIX 1:

INTERVIEW CHECKLIST

Interview Questions / Checklist

1. Individuals with diabetes

1: General Health

Compared with other people that you know would you consider yourself healthy?

Why's that?

Is your family healthy? Why/ Why not?

What does 'healthy' mean to you?

What does a healthy person look like?

What can you do to stay healthy?

Do you wish you were healthier?

How do you rate the health of people in your community? Why?

What would rate as the top 3 health concerns in your community?

2: Illness - consequences

Are there things that get in the way of you being healthy?

What type of symptoms tell you that you are no longer healthy?

If other illnesses mentioned

What do you feel are the causes of these illnesses?

What are their symptoms?

Do you see these illnesses as related?

3: Community

How would you describe your community?

Are there some things that you would like to change in your community?

What kinds of things would you keep the same?

4: Diabetes

(a) diagnosis -

Is diabetes a health concern in your community?

Can you tell me about the events leading up to being diagnosed with diabetes?

What was that like for you?

What sort of information about diabetes have you been given?

Where did you get this information?

What have you been told since then?

(b) living with diabetes -

What is it like to live with diabetes on a daily basis?

How is your life different from before you were diagnosed with diabetes?

Has the transition been difficult?

Can you describe any changes in how you felt about your body after you were diagnosed with diabetes?

(c) Cause

What do you feel is the cause of diabetes?

Do you think that there is a difference between how you see diabetes and how the medical community views diabetes?

If yes - What are these differences?

If no - How are they similar?

5: Treatment of diabetes

How do you deal with your diabetes?

Ignore it - Why do you ignore it?

Do you think that the way that you deal with your diabetes works?

(a) Traditional approaches

Do your friends or family suggest any Aboriginal approaches to diabetes care?

Do you use the programs offered by the community?

Which of the ways that you deal with your diabetes do you feel works best for you?

What about this treatment is helpful?

(b) Biomedical approaches

What about doctors? What do they do for you? Is that helpful?

Can you give me an example?

Do you see the doctor regularly?

What happens at these meetings?

Do you see anyone else for your diabetes - who? about what?

6: Complications

Have you had any complications with your diabetes?

If yes Can you describe what this experience was like for you - how you felt?

Do you see diabetes differently now?

Did this experience change how you felt about your body?

How did you treat these complications?

7: Response of family/friends

Do you talk about having diabetes with friends or family? - or is it something you would rather not think about?

Do you find that your friends or family have treated you differently since being diagnosed with diabetes?

If yes, Why do you think that is?

8: Perceived scale of the problem

Does anyone else have diabetes in your family?

Do you consider diabetes to be a problem in your community?

When you say you consider diabetes to be a 'problem', what do you mean by the word 'problem'?

Do you view it as a personal problem or a community problem?

If community How do you know that it's a community issue?

When according to you did diabetes begin to be a problem in your community?

Has the problem improved since then?

9: Prevention - future recommendations

In your opinion, is there anything that can be done to prevent diabetes?

If yes - What is it?

What else needs to be done to help solve the problem of diabetes in your community?

Is there anything that is being done right now that should be changed?

Do you think diabetes will ever stop being a problem?

What kind of signs would indicate that there has been an improvement?

What do you think is the overall best solution to dealing with the problem of diabetes?

What would you like to see happen?

10: Demographics

-age / education / occupation / residence

2. Health Care Professional

1: General Health

How do you rate the overall health of this community compared to other communities that you have worked in?

When you use the term 'healthy' what do you mean by it?

In your view, what does a person need to do to stay healthy?

What does a healthy person look like?

What do you consider to be the top three health concerns in this community?

2: Diabetes

Is diabetes a concern for this community?

What are the mechanisms in place to help identify/diagnose people with diabetes?

What are the symptoms of diabetes?

Is diabetes a problem in this community?

What do you mean by that?

Are more people being diagnosed with diabetes now than there were 5 years ago?

Why do you think that the number of people being diagnosed is increasing?

Can you tell me about the process of diagnosing diabetes?

What type of information do you give someone diagnosed with diabetes?

3: Cause

What causes diabetes?

As a health care worker do you feel that your Aboriginal patients deal with diabetes effectively?

In what ways could they improve how they treat their diabetes?

In your opinion, is the Aboriginal community receptive to treatments offered by the health care centre? Do you think there is room to improve programs? How?

Do you feel that diabetes is perceived differently by Aboriginal patients?

If yes: In what way?

How do you perceive diabetes?

4: Treatment

Could you describe what is meant by 'diabetes management'?

Do you feel that this type of management is effective?

Do you feel that the medical treatment offered by the health centre has been effective in this community? *If no* - why not?

(a) Compliance/ non-compliance

Do you ever encounter a lack of compliance with the treatments proposed?

If no, What do you put that down to?

If yes What do you feel is behind this lack of compliance?

(b) Traditional/ non-traditional treatments

Are you aware of any treatments, beyond those offered at the health centre?

What do you know about Aboriginal approaches to diabetes?

How do you feel about them?

Do you see any conflicts between them and the treatment offered at the health centre?

If yes What steps could be taken to alleviate this problem?

(c) Education

Does the health centre provide diabetes education sessions?

If yes How often? Could you describe one of these sessions for me?

How do you access people? Are they well attended?

5: Prevention

Is there anything that can be done to prevent diabetes in this community?

If yes What is it?

Could you give me some examples?

6: Future recommendations

If things continue to go on as they are now do you feel that things will improve in the future?

What kind of signs would indicate that there has been an improvement?

Do you believe that there is a solution to the problem of diabetes?

If yes What is it?

If no Why not?

7: Community

Could you describe this community for me?

Have you worked in any other communities?

Is it different from other communities that you have worked in?

If yes In what ways is it different?

How do you view your role as a health care worker in relation to this community?

8: Demographics

-age / education / occupation / residence

3. Community members without diabetes

1: General Health

Compared with other people that you know would you consider yourself healthy?

Why's that?

Is your family healthy? Why/ Why not?

What does 'healthy' mean to you?

What does a healthy person look like?

What can you do to stay healthy?

Do you feel you are able to do these things?

Do you wish you were healthier?

How do you rate the health of people in your community? Why?

What would rate as the top 3 health concerns in your community?

2: Illness - consequences

Are there things that get in the way of you being healthy?

What type of symptoms tell you that you are no longer healthy?

If other illnesses mentioned

What do you feel are the causes of these illnesses?

What are their symptoms?

Do you see these illnesses as related?

3: Community

How would you describe your community?

If you could change three things in your community what would they be?

What would you leave the same?

What are the things you worry about most - i.e.. health, employment, family?

4: Perceptions of health care system

Have you ever accessed the health centre in your community?

Do you find it is helpful in addressing health issues in your community? Why, why not?

Do you visit a doctor regularly? Do you find it useful?

Are there better ways to ensure that you stay healthy?

5: Diabetes

Do you consider diabetes to be a problem in your community?

Do you view it as a personal problem or a community problem?

If community How do you know that it is a community issue?

What do you think the level of awareness about diabetes is in the community?

When according to you did diabetes begin to be a problem in your community?

Has the problem improved since then?

Do you feel that diabetes is discussed openly in the community?

6: Level of concern

Are you concerned about developing diabetes?

Are you concerned about friends or family developing diabetes?

If yes What is it about diabetes that concerns you? - changes to your body, changes in relationships?

7: Causes

What do you feel causes diabetes?

Do you feel that diabetes is related to any other illnesses in the community?

How is it similar?

How is it different?

Are there ways to know if someone is diabetic?

Does someone being diabetic change how you perceive them? How?

Are their bodies different?

8: Prevention

Do you feel that diabetes can be prevented? How?

What would you like to see done?

Are there things that you do right now that might help to prevent diabetes?

What are these things?

9: Treatment

Are you aware of types of treatments for diabetes?

What are they?

Which do you feel would be most effective?

10: Future recommendations

If things continue to go on as they are now do you feel that things will improve in the future?

What kind of signs would indicate that there has been an improvement?

Do you believe that there is a solution to the problem of diabetes?

If yes What is it?

If no Why not?

11: Demographics

-age / education / occupation / residence

APPENDIX 2:

COMMUNITY REPORT

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Executive Summary

This report outlines Aboriginal and biomedical perceptions of non-insulin dependent diabetes mellitus (NIDDM) on Manitoulin Island. Information is based on a series of unstructured interviews in the communities of Birch Island and Sucker Creek. Those interviewed included: 15 individuals with diabetes; 13 individuals without diabetes; and 18 health care providers.

Clients and health care providers utilize different definitions for health. Clients define health holistically, referring to a balance between mind, body, spirit and emotion. In contrast, most health care providers described health in physical terms, evident in their focus on the impact of obesity on health. Further differences were found when discussing the appearance of a healthy body. Specifically, clients perceived a larger body to be healthier whereas health care providers did not. This perception may create a barrier between health care providers and clients when emphasizing obesity as a risk factor for diabetes.

Both clients and health care providers considered diabetes to be the most significant health issue facing these communities. Most clients described diabetes as a recent occurrence. In contrast, health care providers stated that the perceived increase in diabetes is partially due to a larger population coupled with increased diagnosis.

Further differences between clients and health care providers were evident in stories dealing with causes of diabetes. The majority of community members considered the cause of diabetes to be genetic. Specifically, they suggested that Native people are pre-disposed to diabetes. Additionally, certain events in the external environment - such as stress and dietary change - may trigger the onset of diabetes in individuals who are genetically predisposed. An emphasis on genetics in causation implies that Native bodies are different from non-Native bodies and that this difference is based in biology. As a result, the onset of diabetes is largely considered inevitable for First Nation's people. In this sense, perception of cause may pose a barrier to prevention. In contrast, the majority of health care providers attributed diabetes to poor lifestyle habits and obesity.

For the majority of clients, diagnosis occurred when they were at the doctor for reasons other than symptoms associated with diabetes. Due to this circumstance, many individuals articulated being shocked or angered at the time of diagnosis. The result of this reaction was often denial. In this sense, the emotional consequences surrounding diagnosis can be considered a potential barrier to further treatment.

For diabetes treatment, most clients mentioned a preference to use traditional medicine over biomedicine as they consider it to be more effective. The effectiveness of traditional medicine is attributed to its ability to treat the *source* of the illness, rather than the *symptoms*. Nonetheless, in practice most clients use a combination of both traditional medicine and biomedicine. Both clients and health care providers were positive about future collaboration between traditional medicine and biomedicine in relation to diabetes treatment - although there remain a number of barriers to be addressed before collaboration can be achieved.

Most clients stated that they closely manage their diabetes and that they are motivated to do so based on an awareness of secondary complications and a fear of insulin injections. There is also a sense of individual blame surrounding disease progression. In contrast, the majority of health care providers perceived client management of diabetes to be poor. This poor management is partly attributed to different definitions for the term 'management'. According to health care practitioners, the most significant barriers to effective management are: a lack of compliance with lifestyle changes; a fatalistic attitude on the part of clients; and communication barriers. In contrast, the majority of clients discussed not being able to afford the food recommended by health care providers, and the emotional impact of having to deal with a chronic disease, as barriers to effective management.

Both clients and health care providers recommended increased education surrounding diabetes. Clients also emphasized that this education must include a cultural focus. Clients also recommended that a focus on mental health issues be a central component of health care initiatives for diabetes.

Introduction

The following report is based on a series of unstructured interviews with individuals in the communities of Birch Island and Sucker Creek. Those interviewed included individuals both with and without diabetes, along with health care providers. These interviews took place from May to July 1998. Health care providers interviewed included doctors, nurse practitioners, nurses, community health representatives, traditional healers, mental health workers, and dieticians. The breakdown of these interviews is as follows:

Total Community members interviewed:	28
Total Individuals with Diabetes Interviewed:	15
• Sucker Creek:	5 (3 male:2 female)
• Birch Island:	10 (5 male:5 female)
Total Individuals without Diabetes Interviewed:	13
• Sucker Creek	5 (0 male:5 female)
• Birch Island	8 (1 male:7 female)
Total Health Care Workers Interviewed:	18

These interviews addressed a specific range of themes in order to establish general perceptions of diabetes. These general themes have been organized in the following categories for this report:

- General health
- Causes of diabetes
- Conditions surrounding diagnosis
- Treatment
- Diabetes Management
- Knowledge
- Consequences of living with diabetes
- Future recommendations

This report seeks to outline the representations of diabetes from a variety of positions, be it doctor, traditional educator, or an individual who has been diagnosed with diabetes. These representations will be provided in narrative form. Following each section a summary will be provided to highlight trends and outline potential implications. All names have been changed in order to preserve anonymity.

General Health

First Nation's Perspectives

Community Health Concerns

When asked what they consider to be the top three health concerns in the community, respondents ranked them accordingly (please note, all respondents were aware that they were involved in research related to diabetes which may have biased this response):

	<u>Birch Island</u>	<u>Sucker Creek</u>
<i>Diabetes,</i>	88% (1)	86% (1)
<i>Alcohol Use,</i>	50% (2)	14%
<i>Obesity,</i>	25% (3)	43% (3)
<i>Lifestyle Related (i.e. smoking),</i>	25% (3)	71% (2)
<i>Heart Disease,</i>	19%	0
<i>Mental Health,</i>	19%	0
<i>Violence,</i>	0	14%
<i>Tuberculosis,</i>	6%	0
<i>Abuse of Prescription Medication,</i>	0	14%

*Mentioned by X% respondents in each community.

Among the respondents, 20 identified having individuals in their family with diabetes. Additionally, there was a strong perception among those interviewed that the occurrence of diabetes is a recent phenomenon. When asked how long diabetes has been around, 24 individuals responded that it is relatively recent, specifically within the last 20 years. Only 7 individuals responded that diabetes is not a recent phenomenon. Elaine discussed the extent to which diabetes has affected First Nations' communities:

"Recently there is like an outburst among the natives. It's all over. Everybody's getting it."

Some individuals, such as Dorothy, mentioned that it may not be a recent phenomenon, but rather that increased diagnosis is contributing to higher numbers:

"I'm not so sure it's really gone up. It's just that maybe now that people have even better access to health services now that they can be diagnosed with those kinds of illnesses or diseases."

Self-Rated Health Status

Among the respondents, 16 individuals stated that they consider themselves healthy. There appear to be no differences between the response of individuals both with and without diabetes. In contrast, 10 individuals stated that they are 'not healthy'. The majority of these individuals have diabetes.

Attitude towards Illness

Among the respondents, 14 stated that they view illness as inevitable and beyond an individual's ability to control. In contrast, 10 individuals stated that they consider illness to be preventable.

Definitions of Health

When asked to define 'health', 8 individuals defined health as a purely physical condition. In contrast, 18 individuals expressed holistic definitions for health. Holistic was often used to describe a balance between physical, mental, emotional, and spiritual health. Dorris stated:

"In light of what I said, to me I think health is being comfortable where I am."

David, discussed the necessary components to achieving a healthy state:

"You have to have a healthy mind, body, and spirit. People have maybe a healthy body, but their mind is all messed up. Spirit and emotions are all screwed up. Maybe their spirituality is missing and their mind starts going and emotions start going, and their body goes last. When your spiritually isn't balanced, your body starts going too. Once something is off, everything else just sort of falls off too".

Many individuals, such as Dorothy, discussed the importance of culture to achieving a state of health:

"And I think when you learn more about your culture, any culture, not just having to be Ojibway, you learn more about your tradition and I just think it heightens your whole, I don't know, your self esteem, your proudness, and just influences your positive part of your life and your health is just going to benefit. Like it's just this ripple effect. It's hitting all these positives throughout."

Margaret re-iterated this perspective:

"Culture and language, that also is part of your health. Because if you don't have those, you're not healthy in that sense."

Health and Body Size

This section will outline the relationship between body size and health. This discussion will explore what 'health' looks like. It is of particular relevance for diabetes, due to the emphasis placed on obesity as a risk factor.

The majority of the respondents (18 individuals) articulated that a healthy body is one that is neither too thin nor too large. David stated:

"I always have a little extra just in case I'm out there somewhere and I run out for a few days. If I was totally fat free, my body would need to be constantly charging. If I have a little bit on me, say a few extra pounds over, not 20 or 50 or 100, but enough to just ... say I ran out of food and I was stuck and walking or going far, at least I'd have enough to get to somewhere

else. You need a little bit to be in good health. If you have too much, then you get all stressed out. You feel shitty, you look shitty, and you become shitty. It just sort of follows.”

Mary articulated that a healthy body size depends on the individual:

“I think if you’re at a healthy weight, whatever that is, for every person it’s different, then you should be ok”.

When asked whether it’s healthier to ‘have a bit of weight on’, she responded:

“Yea, to have some meat on you.”

Others, such as Doris, described how losing weight would be an ‘unhealthy’ venture according to a holistic definition of health:

“You take one part of the pie, cut it up. Everything is kind of related. See, for example, if I were to lose weight, I would have to do a lot of self talk for myself first and try and make realistic goals. First it begins with the mind. If I’m going to lose weight I’ve got to do it in a good way. What is comfortable for me. But sometimes I find when I think of diet, you take the ‘t’ it means die. To me it’s just moderation. How much you’re going to take. That’s what it boils down to. To me it would be unhealthy. I did go on a diet. I’d lost, I think I went down to 150 one time, through a dietician. But that’s following their ... ok you’ve got to eat this, this is the amount that you’ve got to eat. And I had to really think about it. Especially with my grandmother. My grandmother taught me, said, you were born with big bones and you come from a line where there’s women with big bones, so why are you doing this?”

In the following dialogue, Dorothy discussed the acceptance of body weight and distinguished between Native and non-Native perceptions of weight:

Interviewer: “Do you think weight is something that preoccupies people at all?”

Dorothy: “No.”

Interviewer: “Ok. So people don’t worry if they are overweight?”

Dorothy: “No, I don’t. I don’t think you have ... well I don’t know if this is really true, but I don’t think you have too many anorexic or bulimic Nishnaab’s cruising around. Not to say that, for any age group I think, there is some probably going down to that age like with all the pictures of Kate Moss, or trying to be like a Spice Girl or that kind of thing....But I don’t think it’s as rampant as maybe in your culture.

Additionally , 8 individuals explicitly mentioned that they consider it unhealthy to be thin. Elaine stated:

“I think that people that are really, really thin, I think there’s something wrong with them. It comes to my mind for some reason. And that’s why I don’t want to get really, really skinny.”

Doris had a similar perspective:

"I've seen skinny people and I've said, hmm, I don't know is that healthy. They might be skinny but you wonder are they really happy though?"

A similar perspective is articulated by Mary, in the following dialogue:

Interviewer: "Do you think the body sizes of the people we see on TV all the time

Mary: "Skinny women?"

Interviewer: "Yea. Do you think that that's healthy?"

Mary: "No I don't. That's gross."

Nonetheless, 4 individuals explicitly mentioned that they consider it unhealthy to be overweight. When asked what a healthy body size would be, Margaret stated:

"Overweight no. But then again some people think that you have to be big to be healthy. And that's not the way it is".

An additional 8 respondents mentioned that they consider it healthy to be thin.

Biomedical Perspectives

Community Health Concerns

According to the health care professionals working in these communities the top health concerns were as follows:

- 80% stated Diabetes
- 70% stated Alcohol use
- 60% stated Obesity
- 40% stated Mental Health

Among the health care professionals, 7 individuals described diabetes as a recent problem. In contrast, 9 individuals stated that they did not consider the occurrence of diabetes in First Nations communities to be a recent phenomenon. Many described an increase in population size coupled with increased diagnosis resulting in the perception of an increase in diabetes. John described this perspective:

"The literature makes me understand its probably been an issue for at least 30 or 40 years. But before that it may have been there but we weren't picking up on it. Other things were more important, like infectious diseases. Now that we've cured a lot of those problem, other problems that have always been there and been a problem are becoming more important. For example, if you're in Africa dying of AIDS you're not going to worry about your cholesterol level. Other things take precedence. I would say why we're seeing more diabetes now, is that we're diagnosing more, that the criteria of

diagnosis has dropped. ...People are more aware of disease. More people are asking to be checked out. Making more diagnosis. Because you make a diagnosis earlier you have diabetes longer, so they're living in the community longer. The prevalence has gone way up and the incidence has gone up a little bit.

Perceptions of Community Health

When asked to characterize the health of these communities as 'healthy' or 'not healthy', all respondents stated 'not healthy'. When asked to elaborate upon why they consider these communities to be unhealthy, 9 of the health care professionals attributed their poor health to personal lifestyle issues. As a corollary, 16 of the respondents discussed obesity as contributing to a lack of health.

The relationship between personal lifestyle and health became apparent in discussions surrounding diabetes. According to Karen:

"In other places, pop and chips are kind of out. People don't really do that anymore. We do tend to be behind the times on the island I think. Whether that's sort of self-inflicted, I don't know. But I think we need to catch up to what everyone else is doing, as in living healthier lives."

Related to this discussion of 'healthier lives', is the perspective that individuals in the community do not actively pursue health. This perspective becomes evident in Robert's discussion of the length of time diabetes has been a problem in these communities:

"It's been a problem for years really. And then you get the diabetes running in families too. You get one or two people and then you start fishing around and then you find that the whole family back to a grandparent, are all diabetic, and didn't do anything about it mostly."

Obesity

In discussing general 'health', the occurrence of obesity was consistently mentioned as contributing to 'poor health'. According to Karen:

"I think looking at obesity is a big problem in any area. I think in the general population there are probably more people that are grossly overweight, like more than 10, 20, 30 lbs., but more like 50 or 100. So that's a big health problem."

John had a similar perspective:

"A healthy body is someone that when you look at them they don't appear obese."

William discussed the relationship between obesity and diabetes:

"An obese body is more likely to develop health problems and that in populations where there is a higher degree of obesity there is definitely more health problems. And the majority of people that we have in the First Nations population who are diabetic are also obese."

Many of the health care workers discussed the existence of different perceptions of weight between themselves and their clients. According to Karen:

"And again it's more acceptable to be like a good 50 or 60 lbs. overweight. I'm actually quite surprised myself...like when I look at someone and I think, oh. Like in my mind I'm sort of thinking if they lost like 20 lbs. they'd probably feel a bit healthier themselves. Because you're carrying extra weight for your heart and everything. For your joints. And they feel comfortable at that weight. Like people that are 5'2" and weigh 160 or 170 lbs., actually I've heard them say to me and to other people that, no I feel good about my weight, I like this weight. I just don't want to put any more on. Whereas, I think like ooh, you're going to end up with problems later when you're older and your metabolism slows down.... the image is different."

Beth discussed similar cultural differences observed in the response of community members to a display at fitness week:

"No, I don't think people think that around here that that little skinny toothpick kind body is good. They don't see that image as positive. As a matter of fact, for our fitness week there we did a display on the wall there, and the girl that was sitting here she usually tries to help me out with the display board, her pictures that she put up to show people running and using different equipment and stuff, the pictures were of these really pretty thin women and I don't know how many people pointed that out to us..."What's this. Look at these people. How come they're all so thin?" And I thought that was good that they did that...It wasn't realistic to them."

Summary

This section has outlined differing perceptions of health from the point of view of community members and health care practitioners. On the part of community members, the majority considered themselves healthy (including those with diabetes). In contrast, the majority of health care practitioners characterized these communities as unhealthy. These differences may be due, in part, to differing definitions for health. The majority of community members emphasized holistic definitions for health. A holistic definition implies that maintaining health involves more than sickness care and asserts a place for 'culture' in the pursuit of health. In contrast, health care practitioners emphasized the physical impact of poor lifestyle, such as obesity. Thus illness, according to the health care practitioners interviewed is largely preventable and is based on individual lifestyle choices. In contrast, the majority of community members viewed illness as inevitable. Also identified in discussions of health were different perceptions of a 'healthy body'. According to community members a larger body was described as healthier. This perception may create a barrier between health care practitioners and clients when emphasizing obesity as a risk factor for diabetes.

According to community members diabetes is a recent phenomenon. In contrast, a number of health care practitioners mentioned that increased occurrence may be due to increased diagnosis and a larger population. Describing diabetes as a recent

occurrence on the part of community members is related to the perception of cause. The following section will outline causative factors from the perspectives of community members and health care providers.

Causes

First Nation's Perspectives

This section will outline what community members articulated as *causes* of diabetes. Differences between either Sucker Creek and Birch Island or diabetic and non-diabetic individuals will be outlined.

The 'causes' outlined for diabetes were varied and include the following: genetics; dietary change; chemicals and pollution; stress; alcohol; lifestyle issues; and obesity. It is important to mention that for many individuals a number of causes were outlined. As will be evident in the narratives, the perceived cause of diabetes can have an important influence on how people choose to respond to it.

I will begin with the two most frequently cited causes: genetics and dietary change. Upon first inspection, these two causes seem to be in opposition: that is, one represents a biological explanation and the other an explanation based on societal change. Nonetheless, over half of the people who discussed genetics, also discussed dietary change as a causative factor. When asked specifically to choose between the two – genetics was most often chosen. The first possible explanation for this overlap is that people perceive a combination of potential causes. The second possible explanation is that although there is an awareness of the importance of diet and lifestyle, this knowledge is not in line with people's experience of diabetes as something that 'runs in families'.

Genetics

Approximately 20 of the respondents outlined genetics as a causative factor. Genetics was discussed with greater emphasis in Birch Island than in Sucker Creek. There do not appear to be differences between diabetic and non-diabetic individuals.

Annie from Birch Island stated:

"What do I think causes diabetes? Well for the better part of my life I maintained my health. I watched my diet but I got it somewhere along the line. Genetic. I would think it would be."

Gloria, also from Birch Island said:

"Well I think, getting back to some of the outside factors like the diet and how active you are, but I think it's in the gene pool. You're born with it. Just like any other disease, in terms of the medical history in your family, some people are just more prone to certain diseases than others. For sure that's where it comes from. But I mean there's those extenuating factors too that

play a big role in making it worse than it ought to be maybe....Yea. I really believe it's part of your gene pool or history in terms of family."

Emily's discussion reveals an inevitability or fatalism about the occurrence of diabetes:

"My sons have a friend that is diabetic and he kind of got it at a younger age. And they were kind of really shocked about it I guess when they found out that he was diabetic. I had to pass on my information to him from what I know causes diabetes. They kind of understood it. They understood what I meant when I said that it's hereditary. So then they were telling me one day, they said, well eventually we'll all probably be diabetic then."

David, a young man from Birch Island discussed a similar sense of inevitability:

"I was aware of it and I was thinking it's hereditary and it's the family. I'm wondering who's going to get it. Who's ticket is up."

Related to an inevitability about the onset of diabetes, is a lack of control once the disease occurs. Jesse from Birch Island explained this lack of control in greater detail:

"Everybody has it. The only thing is it comes out in some people, and some people it doesn't come out. And some people will say, oh I have borderline. There's no such thing as a borderline diabetic. It's either you have it or you don't have it. If it decides to come out, it'll come out."

When asked about personal responsibility for the onset of illness, Eugene from Birch Island stated:

"I figure like I said I may have contributed but I feel that's beyond my control. It's like aging. There is nothing you can do but you can age gracefully or you can age too fast. You can mitigate against it but you can't really stop it."

The relationship between genetics as cause, and individual response to diabetes is evident in Emily's statement. When asked if it is possible to prevent diabetes she stated:

"I don't think so because once they say it's hereditary, it's hereditary. It runs in the family."

Gloria elaborated on this relationship:

"I think in our community it's not preventable but I think people can live with it in a healthy way. Because we have so many people and they're of course like diabetes could be a genetic disease as well. Like if your parents have it or whatever, maybe two generations down the line. They're more susceptible to getting diabetes. So I don't think it's really preventable."

Mary, a young woman who does not have diabetes, discussed her attitude towards prevention:

"If you take care of yourself? Isn't this supposed to be like a hereditary issue? So I don't know if you can really prevent hereditary, unless you play with your genes, I don't know."

As previously mentioned, many respondents discussed both genetics and dietary change as causative factors. David, a young man who has recently been diagnosed with diabetes explained the relationship as follows :

"They say it's hereditary but I'm not quite sure. I think it's ... like we probably all have the natural weak gene that causes diabetes. It just depends on the lifestyle that you live in order for it to kick in. Maybe I was pushing mine so far that it maybe took long enough to really break it down finally and said, ok well, I can't handle all this sugar."

When asked to describe the importance of both factors, Cyndy from Sucker Creek , outlined their relative importance:

"I would probably put genetic at probably about 80%, maybe 20 at lifestyle. That's just my own personal belief."

The most comprehensive and in-depth explanation of this relationship was provided by David:

"Just the lifestyle. All native people live a stressful lifestyle. Like the lifestyle that they live they're stressed out. Trying to cope in a society that's not traditionally like the way we used to follow, so we changed that a lot. And not eating the proper foods that we used to eat. My dad says if it doesn't run, don't eat it. If you can't catch and kill it, don't eat it. Or if it doesn't swim fast, don't eat it. Or if it's just standing there, then it's probably lazy meat you're eating. And all the other things. Like we never had sugar or sweetness. It used to come in only in berry form in the summer. The other sweetness we used to get was in the spring time with maple syrup only. That would just be once to cleanse the whole system or whenever for that season. If you drink enough syrup whatever, it just goes right through you. And that's all the sugar you would get for the next long while. So lifestyles one of them. There other thing is because of contact and change and influence from non-native society, there's different foods that come in to play like look at all these black forest cakes and stuff. These guys are eating it and their body, like for ten thousand years it was only eat meat with no salt or bears and stuff like that. Food that they come is all different and there's different ways of cooking it. And a lot of it is frying. Just clogs you all up and everything. It just causes poor circulation. On top of it you're jamming sweets in there. There's something else to pump through. It's like running a garden hose, pouring oil and pouring sand and grass and gravel in there trying to make that hose run clean. That just doesn't work when you're so used to just having water run through it. So I think it is probably a lot of the foods. But at the same time too there's another introduction of alcohol which gets to a lot of these people. Their lifestyles are all fucked up. They don't have a job. There's no community support like to find work. There's nothing to do except get into a state of depression, they're eating junk, they're unhealthy, they're getting fat, lazy, and stupid. Then they're starting to drink

on top of that. Oh that's an escape for a little while and then it becomes like their reality after. On top of that there's a lot of sugar in alcohol and stuff like that. So all those things mixed. Like they're not all going out spear fishing, hunting, or catching what we used to catch to eat that would maintain their body health. So they're just sitting around drinking. Inactivity that clogs you up even more. On top of the alcohol it's really screwing up a lot with you too. So there's three major factors and all of a sudden diabetes is hanging around waiting for somebody to get all fat and lazy and whatever saying there's my next victim. The only thing is there are others like myself that have been constantly working doing stuff all the time, eating right, and then it affects so there's probably a genetic thing there too."

There are a number of emergent issues in this passage. Much of this narrative centres on the concept of change – alternating between descriptions of past lifestyles and contemporary ones. Further there is an identification of native bodies as different, evolving in a different environment, and thus contributing to the toxicity of the contemporary lifestyle in relation to these bodies.

Within this passage, the onset of diabetes is attributed to a number of related issues. Firstly, this narrative identifies that the contemporary lifestyle has had a detrimental impact on Aboriginal people. Secondly, this narrative articulates that the contemporary lifestyle is different due to contact and change. Thirdly, this narrative suggests that the impact of this change has led to alcohol use and a lack of community support. And finally, within this narrative there is a perception that the combined effects of these factors is resulting in the onset of diabetes. Diabetes represents an inherent (yet hidden in the form of a 'weak gene') quality of these individuals waiting for the optimum conditions to make an appearance. The discussion to follow will outline external factors that were described as potential triggers for diabetes.

Dietary Change

Dietary change was mentioned as causative by 23 of the individuals interviewed. Nonetheless, there was less emphasis placed on dietary change as cause than genetics in the actual text of the interviews. There appear to be no distinctions between individuals who have diabetes and those who do not.

Dietary change is often discussed in the context of other changes in the lifestyle of First Nation's People. Doris, from Birch Island, placed the occurrence of diabetes into historical perspective:

"I know diabetes is high here compared to the other First Nations. I don't know if it's because we have closer access to process foods. I don't know, that could be it. People are not into traditional foods. You know we don't hunt as we used to. There's only a few families that do and they just share it. I guess it's re-learning, especially the next generation, re-learning how to prepare those foods."

Cyndy, had a similar perspective:

"Well then again it's probably, we don't eat the same way we did 30, 40 years ago. I can remember my grandmother cooking things like corn soup

and not necessarily everything fried. So I think we've come into the western world of eating. We still eat our native things, but we cook them differently now. I would think that's the reason."

Dorothy, a young woman from Birch Island, related the effects of Western foods on Native people to differences between Native and non-Native bodies:

"But I think just in terms of just our lifestyle and our diet, I think even studies of the Inuit people who just ate raw fish basically in the Arctic, and then they didn't have that lifestyle or that traditional way of food gathering, and they went into processed foods like cheese, macaroni, like a lot of pasta kind of dishes too. All of a sudden their body metabolism is introduced to this new foreign dish so to speak. And I think that's what happened to us essentially, but I think they're a better example even more recently in terms of contact, that kind of thing. I just think our body metabolism is a little bit different than non-native people. If we had been introduced to that kind of food even longer ago, maybe we wouldn't, you know the effects over let's say 50 years, wouldn't be as horrendous maybe."

Eugene discussed the role of the external environment in causation:

"I'm starting to think that maybe this diet plays a big part in your body-the general chemistry, the functioning of your body. Just because you have a layer of skin separating you from your environment doesn't mean that you're not immersed in your environment totally and what's put into your body has an effect."

In discussing diabetes as a recent phenomenon, many individuals related dietary habits to their larger social context. Evelyn, from Birch Island, explained it as follows:

"Why did it show up 14 years ago? The age group that it has hit has been those that came through, that survived the drug and alcohol stages. Some then some of the poor eating habits which again stems from the abuses that they've had."

Margaret, had a similar explanation:

"Hmm. Yes it has a lot to do with the change in diet it has. And I think the worst part of it is why people are overeating and not looking after themselves is again lack of employment, lack of services, housing."

In this sense, poor dietary habits are related to larger sources of stress, such as abuse and unemployment, originating in the socio-political environment.

Chemicals and Pollution

Chemicals and pollution were mentioned as causative factors by 10 of the respondents, with equal emphasis in both Birch Island and Sucker Creek. This category includes cases where chemicals in processed foods are outlined as causative, as opposed to the more general changes in diet previously discussed.

Bernard, from Birch Island, discussed current changes to the environment:

“We’ve got air pollution now. Everywhere I guess. Like the water used to be clear and fresh around here; it’s not anymore.”

Jesse shared Bernard’s perspective and discussed the impact of this pollution on health:

“A lot of people, the way they probably eat causes [diabetes]. I wouldn’t trust eating fish from the lake now myself. What do they call that water? Pollution.”

Raymond, from Birch Island re-iterated this theme:

“Well it’s the food they eat. A long time ago there was wild meat, but now we eat food that is treated. They give animals certain things, I don’t know, like chemicals and that’s what we eat.”

This pollution is described by Dennis, as having particular effects on Native people:

“There’s chemicals in the meat. You go into the store ... the meat is already chemical. Your potatoes are chemical. Your vegetables are chemical. What are you going to do? You feed your rabbit that, your tame rabbit that, he’d get sick. Yea, it’s the food. What’s in the food and what you eat, and somehow or another some people can’t overcome the diabetes. But it’s mostly native people.”

Within these statements the onset of diabetes is related to chemicals and pollution in the external environment. Chemicals and pollution are defined as having particular effects on Native people, thus explaining the higher rates of diabetes in Native communities.

Stress

Stress was identified as causative by 13 of those interviewed. Additionally, stress was most often emphasized by individuals who also discussed genetics as causative. Stress was most often emphasized as a causative factor in Birch Island, and among individuals diagnosed with diabetes.

Stress is discussed in the context of individual lifestyle factors: specifically, that people with stressful lives tend to have poor lifestyle habits. Nonetheless, the discussion of stress as causative is not limited to its influence on lifestyle. Indeed, in the story told by Bernard in Sucker Creek, stress is explicitly described as a cause:

“Ok. Well I’ll tell you a little story that was told to me. There’s this old couple, 75, 76-years-old, going for a check-up every 6 months, and they are just as healthy as could be. No problems for the 6 months. All of a sudden, both of them with diabetes. The next 6 months the doctor found diabetes in them. He couldn’t figure out. He went back and checked what they ate and what ... they were eating properly, nothing wrong. So finally he just asked them. Anything happen in your family? They had lost a grandchild in a car accident. So knowing that, that’s what triggered it I guess. Maybe it had

been going on for awhile, but this thing triggered it. Both of them had it at the same time. That's what I was told and they said that stress is about the worst thing about in diabetes. And there's a lot of it for native people. Like I said, being out of a job and not having enough money. This sort of thing causes stress."

The mechanism through which stress affects the body is outlined by Doris:

"We don't learn how to trust and how to feel. So when you don't release all that stuff out, it stays in there and it just builds and builds and builds. Like I have heard an elder that made me think about it, he said something that made a connection to arthritis--that is a lot of anger built up. And I'm going, now why would that person say that. It takes time to be a diabetic I guess. But I don't know. For native people it's a high number after 40"

In this statement, the high amount of diabetes found after the age of 40 is attributed to the accumulation of stress over the years. Evelyn further discussed these effects:

"Because your body gets quite eaten up too. Unless you find ways of handling your stress."

Lifestyle

Lifestyle is mentioned as a causative factor by 8 of the respondents, and most emphasized by those individuals who have been diagnosed with diabetes. Related to a discussion of lifestyle as cause, is the issue of personal responsibility for the occurrence of illness. Eugene described this sentiment:

"But then there's a little bit of a factor that puts some of the blame on you and wonder, gee maybe if I wouldn't have drank so much-I was going to say party-if I hadn't drank so much when I was young, if I would have contributed to my state."

Alcohol

Alcohol is also mentioned as a causative factor by 8 of the respondents. It was most emphasized by individuals in Birch Island and also by individuals who did not have diabetes. According to Mary:

"I don't know. I'm not too sure... I find a lot of people that have it around here used to have an alcoholic problem so I think that has a relation to it."

Bernard also mentioned a similar relationship:

"I noticed that a lot of people that used to drink a lot of wine, a lot of them were diabetics. I was more a beer and whiskey drinker myself."

Obesity

Body weight was mentioned by 8 of the respondents as a potential cause of diabetes. The relationship between body weight and diabetes was most emphasized by individuals who have diabetes.

Rachel, from Birch Island, explained the relationship between her own diagnosis and body weight:

“I don't know. Maybe it's just, well maybe we don't ... maybe exercising or stuff like that. Maybe that has a lot to do with it. Our weight and stuff like that. I was way heavy a few years back. I was almost 200 lbs. So I had to go on a diet and lose some weight when I was told I was a diabetic.”

Summary

The emphasis placed on the role of genetics in causation has a number of implications. Firstly, an emphasis on genetics in causation implies that the disease is not preventable. Secondly, this perception distinguishes Native and non-Native bodies. That is, it implies that Native bodies are different and that this difference is based in biology. As a corollary to this perception of a different biological make-up, community members often articulated that diabetes was “triggered” by an external occurrence. Therefore dietary change is described as causative due to its particular impact on Aboriginal bodies. Similarly, chemicals, pollution, stress and alcohol were described as ‘triggers’ for diabetes. Each of these external processes is linked to larger processes of change that have taken place in the community - linking the occurrence of diabetes to these changes. This account of causative factors may make it possible for individuals to identify a number of causes without perceiving any apparent contradictions. Specifically, that genetics forms the foundation upon which other causative factors act. What is evident in these narratives is that the occurrence of diabetes is defined as *collectively* affecting Aboriginal people. Lifestyle issues and obesity were mentioned, but to a lesser degree and mainly by individuals who had previously been diagnosed. Mention of these factors by a minority of individuals may have been influenced by the biomedical literature surrounding causation.

Biomedical Perspectives

Lifestyle

Among health care professionals, 16 attributed the occurrence of diabetes to individual lifestyle factors. According to Karen:

“I think people's eating habits, their exercise, their weight. I think it's more things that you can control that are out of control that's causing the high rates.”

Similarly, Nancy stated:

“I think because of lifestyle issues. I think the diet is very important. This would take a long time to change. There's a lot of people who eat a lot of fat. It seems to be their favourite foods. Some people don't want to change that.”

Michael discussed the relationship between lifestyle factors and an increased occurrence of diabetes:

“At the same time as it increases, people are probably moving farther away from an active lifestyle... Everything else is useless if people don't follow the lifestyle changes.”

Expanding on the importance of lifestyle factors, Beth specifically discussed the role of diet:

“Well you can't really say that, oh it's the white people that have brought this disease here. But it's something that came along because of the changes in the diet. You can go back a long time ago with fur traders and fur trading for sugar and lard and all that kind of stuff. These are things that native people never had. And the flour and all that. So it kind of resulted in them eating in a different style. Later on not needing to go hunting and fishing and kind of just buying all their food supplies.”

Obesity

Among the respondents, 11 discussed obesity as a causative factor. According to John's observations, there is a direct relationship between the two:

“I think obesity is a factor, you see more diabetes in the Native population and you also see more obesity.”

Charles expanded on this relationship and discussed where to focus health care initiatives:

“I think probably one of the most important things we can teach them is weight control. You don't see a lot of skinny diabetics. You also find that a person who is moderately obese who develops this kind of diabetes, if they got their weight down, they could control it.”

Genetic

Among the health care respondents, 9 mentioned the role of genetics in causation. John emphasized that:

“I think with most cases the cause is genetic.”

William re-iterated this perspective:

“Well, there's a big genetic component. There are people who, with the right set of circumstances, are going to get it no matter what.”

Nonetheless, some of the health care professionals explicitly identified being skeptical about the role of genetics in causation. According to Karen:

“I don't know if you can say genetics. I know a lot of people have said that they think there's a genetic link. I personally kind of looked up some things and I don't really know if I tend to believe that.”

Summary

The narratives of the health care practitioners differ from those of community members in a number of ways. Firstly, health care practitioners emphasize lifestyle factors and obesity as causative factors, in contrast to heredity. An emphasis on

lifestyle factors and obesity implies that diabetes is to a large extent preventable. Secondly, there is a sense that clients do not actively pursue health. That is, they do not engage in lifestyle practices that will promote health. In general these narratives suggest that health is an individual responsibility and health care providers attribute the occurrence of diabetes to individual lifestyle choices. In contrast, the narratives of community members suggest that the occurrence of diabetes is related the collective impact of a number of factors - such as stress, dietary change, chemicals and pollution - on Aboriginal people. This collective impact implies that there is a common basis predisposing individuals to diabetes and a common set of circumstances that trigger its onset. Therefore, for community members diabetes is considered largely inevitable whereas for health care providers it may be preventable.

Discussion of causative factors has also demonstrated that community members have a high degree of knowledge surrounding diabetes. Specifically, there was an awareness of diabetes risk factors. Nonetheless, a sense of inevitability regarding the onset of diabetes may indicate that preventative measures are not realistically achievable for many people. According to the narratives of community members, the pursuit of health is impeded by external factors, such as stress. Therefore addressing these larger factors may represent an integral component of finding effective solutions for diabetes. In this sense, an exclusive focus on individual responsibility by health care practitioners may not be an appropriate direction to take if the proposed recommendations are not considered realistically achievable.

The following section will outline perceived differences between Native and non-Native bodies in order to further emphasize the role of genetics in causation.

Identification of Diabetes as a 'Native Issue'

Specifically Native Problem

Among the respondents, 20 individuals stated that diabetes is affecting the Native population at a higher rate than it is affecting non-Native populations. According to Emily:

"I read, I'd say that the diabetes is mostly on to natives. Natives are the ones that usually have high diabetes compared to others."

Eugene related diabetes to the general occurrence of disease:

"From as long as I can remember a conventional wisdom that natives are predisposed to diabetes. You're susceptible to tuberculosis and apt to develop diabetes. History will support that. Look at when the Europeans came the arrow of disease went our way. It might be a different world today had the arrow of disease gone the other way. But it did and demoralized people. When you see half your people, most of your people die, your leaders, your strongest men, and the few people who could survive were ill. It was not difficult to conquer the nation and for us to lose a lot of tradition. So if it had gone the other way it would be different. I wouldn't say it would be better. So that's a big story to tell."

Often the discussion of diabetes as having a greater impact on Native populations led to a discussion of differences based in biology, specifically differences between Native and non-Native bodies. Gloria described these differences:

“From what I understand from what I've been told as a young girl growing up and going into her adult year, we have a different makeup compared to other nationalities. Even our psychological makeup is different to understand things. That's how we were just made. That comes from our original teachings. We weren't made to ingest pop or things like that. But that's how we were, we weren't like that. And I think our bodies are retaliating. In one way it's saying that this isn't good for you, you got to go back to, at least try and go back a little bit to eating more the natural foods that were given to you in your original instructions. I think anyway. Diabetes is running so rapid on the reserves. Our diabetic rate here is very high... like I said we have a different genetic makeup than other people. You hear that with not only diabetes, but with other things you know like well native people can do this, this. They can withstand this much pain or they have a different understanding of this and that's because we're different. We're not the same as other people. Just like people from India may be different in one way or whatever.”

Not a Specifically Native Problem

Among the respondents, 7 individuals stated that a high occurrence of diabetes is not restricted to Native communities. It is important to mention that a number of individuals strongly disagreed with the identification of an increased occurrence of in First Nations' communities. Eugene discussed his own experience and addressed the issue of 'over-representation':

“But a lot of people I know, like when I'm at school I meet people with diabetes too, and they're not natives and they're taking the insulin. So it's a concern everywhere. Maybe it's must more predominant, just like our over representation in the jails. I don't know who's fault that is. That's another ball of wax.”

The following dialogue with Jesse addressed this issue:

Jesse: “But I don't mean native people. A lot of people. If you went through the communities on the island, you'd see a lot of non-natives with diabetes.”

Interviewer: “So you don't see it as a specifically native problem?”

Jesse: “Not only natives. Everybody. You just can't say, all the native population is the worst off for diabetes. If you probably did the whole study in Canada, you'd see that...It's not just native. It's everybody. It's in your genes or whatever. It's just sitting there waiting for it to come out.”

When Rose was asked how she felt when people discussed a 'greater amount' of diabetes in Aboriginal communities she responded:

“That part makes me mad sometimes. Why pick on the native people. They're not the only ones that have got diabetes. I said I know a lot of white

people that's got diabetes. They are more and more and more... That's what makes me angry when they say that. And I said, why the native people. There's a lot of people out there that's got diabetes. Every time you turn around somebody says they've got diabetes. Why only the native people. A lot of people have got it."

Eugene also summarized how he felt:

"How does it make me feel? That's a good one. I want to pass on that question. Actually you know if I could ... that makes me feel kind of mad and it kind of makes me feel like not as good. You know what I'm saying? Like you can't hack it, you know. So I said it. It makes me feel maybe inferior."

Summary

This section has been included to further emphasize the role of genetics in causation. There is a strong sense among community members that diabetes is affecting the Native population at a higher rate than the non-Native population due to differences based in biology. A perception of difference based in biology – specifically, differences between Native and non-Native bodies - reinforces the perception of illness as inevitable. In this sense, the potential to develop diabetes is an inherent attribute of certain individuals.

Nonetheless, a number of individuals were frustrated and annoyed with the identification of a higher degree of diabetes among Aboriginal people. These grievances relate to a resistance on the part of certain individuals to be labeled sick. The existence of a sense of inferiority or anger at being labeled sick, although speculative, could potentially contribute to tension between health care providers and clients along with corresponding barriers to treatment. The following sections will explore issues surrounding diagnosis and treatment in detail.

Diagnosis

First Nation's Perspectives

It became apparent that most of the individuals diagnosed with diabetes (10 out of the 15 individuals) at the doctor or at the hospital for reasons other than the traditional symptoms of diabetes (i.e. thirst, excessive urination, fatigue). These individuals explained that they were at the doctor for other reasons and were shocked about being told that they had diabetes. In contrast, only 3 individuals described having symptoms that caused them to seek medical attention. In retrospect, some people mentioned that they do recall feeling somewhat fatigued pre-diagnosis.

For many individuals being diagnosed with diabetes was unexpected. Raymond explains:

"They tested me about five years ago. I didn't really expect that you know. When I was in the hospital for another reason they did the blood work."

When asked whether she noticed symptoms pre-diagnosis, Margaret responded:

"No. I wasn't ever thirsty. Or I didn't run to the bathroom. I didn't have none of those. And like I say, they might have been there, but I was busy working and didn't have time to."

Biomedical Perspectives

Similarly, 9 of the health care professionals mentioned situations where individuals were seeking health care for reasons other than diabetes. According to Beth:

"I find a lot of people are diagnosed as diabetic on an emergency type basis. They go in maybe for something else and the doctor, through blood work, finds out, hey you're a diabetic. Or they've had something happen to them and it's because of diabetes and they didn't know they had it."

With specific reference to symptoms, John stated that:

"Probably about a third of the diagnosis are based on symptoms, and those are based on fatigue. Compared to people with the classical symptoms of diabetes, weight gain weight loss. Two thirds are being diagnosed in routine physicals."

Summary

There is a sense on the part of both community members and health care practitioners that the majority of diagnoses are due to individuals seeking medical attention for other reasons. It is unknown whether this is occurring due to a lack of awareness of symptoms on the part of community members, or simply that individuals do not feel sick.

These diagnoses and the circumstances in which they occur are not without consequence. Specifically, that being diagnosed with a chronic disease when one does not effectively feel 'sick' has significant emotional consequences that may not be accounted for within the clinical context of diagnosis. The following section will briefly outline some of these consequences from the perspectives of community members..

Emotional Reaction to Diagnosis

Emotional reactions at the time of diagnosis were varied. Responses include shock, denial, and anger.

For Dennis, who had recently recovered from cancer, being diagnosed with diabetes had this effect:

"I felt like somebody had stabbed me with a big knife...Now what the hell kind of sickness is this?"

For some, the responsibility of living with diabetes was daunting. Elaine stated:

"Yea. It scared me. It scared me to control it. To really look after it."

Many of those diagnosed went through a stage of denial following diagnosis. Margaret relates this experience to other experiences in her life:

“That’s why I was surprised. Like everything else, like through death and illness your first reaction is denial. It’s not me. The doctor’s wrong. It must be somebody else.”

The most poignant response was expressed by David, a young man who was recently diagnosed:

“I was really angry with my doctor around for awhile. I was really mad. I said, what? He says, you’re diabetic. This sucks. I hate this right now. He’s just looking at me and he says, hey calm down. I’m just telling you, I hate to bring bad news, but you’re really going to have to change your tune. I said, ah fuck. Anyway that’s how I felt. I felt really bad and angry. Then sad and depressed after. I went to see a friend ... actually I was going to do everything all over again. I started doing all the bad shit I used to do like drinking and drugs and that.”

The emotional consequences of being diagnosed with diabetes were varied. The fear surrounding diabetes and its complications, and in certain cases denial about the disease itself could potentially influence attitudes towards treatment. Additionally, the shock of being diagnosed with an illness despite a lack of symptoms may potentially result in tension between clients and health care practitioners over the sense of inferiority and anger previously discussed. Thus there are numerous emotional consequences that can be considered significant given the circumstances of diagnosis and these consequences could potentially have a detrimental impact on the treatment of diabetes. The following section will explore client attitudes towards the various forms of treatment.

Treatment

First Nation’s Perspectives

Attitude towards and use of traditional medicine

Among the respondents, 17 mentioned a preference to use traditional medicine over biomedicine. The majority of these respondents (11) are individuals who have diabetes. In contrast, a minority of the total respondents (4 individuals) explicitly mentioned not being interested in traditional medicine. This perspective was most common in Sucker Creek and the majority of these individuals did not have diabetes.

For Margaret, the benefit of traditional medicine is that it influences more than a specific illness, and corresponds with a holistic definition for health:

“Western medicine, it said that they take the best part of the herbs and things to produce what they manufacture. They take out in order to get at what they’re supposed to be using. But the Indian medicine you get everything. It does not only work for one thing, like say high blood pressure.

There's medicines for that, but it also looks after some other part of your body that has to do with why you have high blood pressure."

In addition, Margaret outlined the practical benefits of using traditional medicine:

"I'd go with the traditional medicine. Yea. Because you drink it. This other way, you puncture your little finger every morning. [laughter]"

In these statements, traditional medicine is considered less invasive than biomedicine in addition to having a wide range of beneficial effects. Many of the respondents considered traditional medicine more effective than biomedicine. Annie discussed this perspective and laments not having her grandmothers around to help her deal with diabetes:

"My grandmothers would sure put their heads together to find a way to help me with this problem. Because once when I was a baby, I vaguely remember, my mother took me to Little Current Hospital and she brought me home. The doctor said let her go die at home. She didn't tell me till much later. Years later. Ok. So I remember lying on my grandmother's table and she was giving me something to drink. I must have been, I don't know, 3, 4. Around that age. And it was my grandmother that brought me back to life I suppose. I had lots of trouble I guess whatever it stemmed from whatever, I just remember my mother telling me. I remember bits and pieces of what was I doing on my grandmother's table. I wasn't moving. And I just remembered her lifting my head and giving me something to drink. I knew she was there. I could sense my grandmother being by my side all the time. So mother told me much years later that if it wasn't for your grandmother, you wouldn't be here. And I said, was that what it was about. Because the doctor told me to bring you home and you could die at home here. Apparently, but it was my grandmother that done that. She was big on that stuff."

In this statement, the use of traditional medicine saved Annie's life. The effectiveness of traditional medicine was also evident when Evelyn attributes the occurrence of diabetes to its decline:

"In our culture they're leaving the traditional medicines behind. And with that I would say that that kept [diabetes] in control. I would think that."

A subsection of this group (10 out of 17 individuals) explicitly mentioned that they would like to see traditional medicine and biomedicine somehow combined. The majority of the respondents mentioned using both kinds of medicine in practice. Mary believes that this interest is emerging from the younger generations:

"I think a lot of the younger people are kind of how I am. There should be a harmony. We should put them together and work it together. And I find most of the older people are like, no, no, no, you've got to do it the Indian way because the white man's way doesn't work."

Despite this positive attitude towards collaboration, several of the Elders mentioned problems associated with combining traditional medicine and biomedicine.

Margaret stated:

“Some people say you can’t do both. Some people say if you’re taking the traditional medicine then you shouldn’t be taking the other. Because they fight.”

Dennis had a similar perspective:

“What I found out about the western medicine and they have, you can’t mix them both. Either that, or them medicines will fight together. You’ve either got to leave one, whatever. But you can’t mix them.”

Attitude towards traditional workshops

Among those interviewed, 14 mentioned the traditional diabetes education workshops. Most of these individuals had diabetes, and their attitude towards the workshops was overwhelmingly positive. Annie related her experience:

“When Derrick started here, teaching traditional diabetes education, then voila. It hit home. Then I knew what the heck I was reading about. After all those years he helped me tremendously.”

Jesse outlined how specifically the workshops help:

“The way he talks. Sometimes he’ll say the workshops in our native language. That seems to help.”

Emily explained how they have helped her, although she does point out some problems with accessibility:

“Yea I really like going to his workshops because of all the new things that I’ve learned from there too, and cooking that he was doing. But you know when I first started I didn’t really like it because of, at that time my diet wasn’t changed, like myself I hadn’t changed yet. I kind of miss them because he has them mostly during the week in the mornings. By the time I get home the thing is already over and I have no way to get in.”

Attitude towards and use of biomedicine

Most of the respondents mentioned accessing the biomedical system to varying degrees – whether it be trips to the community health centre, or accessing services provided at the hospital. Jesse outlined her attitude towards biomedicine:

“So when the doctor says, how are you, I say, fine. He says you’re a sick lady. Well it wasn’t only diabetes. I have to laugh though. Me I don’t feel sick. I guess it’s all in the mind. To me anyway. The less you think about your sickness, the more you deal with it. You know you’re sick. But then in your own way if I’m going to be sick, I’m going to be sick. What else can I do about it. Nothing. Just follow what the doctor tells you.”

Others, such as Rose, express a certain annoyance with the advice given:

"The same thing over and over again. What you're not supposed to eat. What you're supposed to eat."

Many times, discussing the role of biomedicine was equated with attitudes towards doctors. For Gregory, doctors were useful for pointing out what he did to promote his own sickness:

"Yea, they can help you. They say, well ok, just what have you done wrong, what did you do? And then they say, well ok, then they tell you what you've done wrong and so listen don't do this too many times because you're going to end up really sick. So it's things like that that."

Others, who are generally positive towards doctors, mentioned a level of distrust around doctors motives with respect to traditional medicine. David explained:

"No, they're really respectful. But there's one doctor, he's always trying to get a hold of stuff. I don't know what his motive is. He wants it. Maybe he's sincere, but I don't know. So nobody gives it to him. It's really hard to trust non-natives."

Elaborating on this 'lack of trust', a number of individuals mentioned being suspicious about the motives of the biomedical system in relation to diabetes treatment. Annie described this attitude:

"There's an awful lot of crooks too you know. This is what the Indians are thinking. Well we have to buy all that stuff. So why are they going to find a cure when we have to turn around and get these things. So they're making money. If they found a cure for everything, well my God. Some say they're holding back because then they can keep us in limbo and we have to keep buying the stuff, whatever you need for all of your diabetes, apparatus."

This statement resonates with previous attitudes indicating a lack of trust on the part of Native clients towards health care practitioners. This lack of trust is often related to issues of power and authority. In this case, the motivation of health care practitioners is questioned due to a perceived relationship between health care and profit making ventures. The origins of this sentiment is further elaborated by Annie:

"Because I'm scared. You don't know what they're going to do. Like you have a sore arm, you get an operation for gall stones. [laughter] That's my version of it. For an Indian they would just say, well you're you know or take these pills and come back and see me next week. ...I'm not a guinea pig....Like he says if it doesn't work, come back and see me in 2 weeks. Well they say here's some rat poison, if it doesn't kill you, you're lucky.[laughter] He said to me you have to take low cal sweetener, and that's the god awful thing you've got to get used to. So I said to the doctor, I says, it was proven that it killed rats. So he says, what are you telling me, you're a rat now. Because I read it somewhere when he told me I went gung ho on the thing. And it killed rats and whatever this low cal thing. So I said to him, is there an alternative. I tried to talk to him for him to talk to me on a one-on-one basis because I'm not smart, I'm not a doctor, I'm not a lawyer. I'm not an imbecile. I can understand the Indian and the English ...But I says, I read

in the brochure that kills rats. Brrr. "So you're not a rat. It won't kill you."
But that's chemical taken into my system... I have to eat it mind you. But
what's wrong with a little bit of honey as opposed to ... I keep honey because
I'm like, well whatever is in there it's like ... But I've created my own sort of
myself experimenting here, get away from sugar.

Summary

When faced with an illness to which biomedicine has no cure, a focus on traditional medicine effectively provides hope where there was none. Additionally, due to the experience of diabetes as a recent disease that has resulted from processes of 'change', a focus on traditional medicine may not only be pragmatically, but also symbolically important to finding solutions. Perceptions of cause are intimately related to potential solutions. Community narratives discussing how 'change' – in the form of diet, lifestyle, stress levels – has led to the occurrence of diabetes may suggest that a focus on traditional medicine in treatment is part of the larger process of "looking back" for solutions.

The general perception on the part of community members is that biomedicine isolates individual illnesses and decontextualizes whereas traditional medicine addresses the wide ranging reasons as to *why* an individual is ill. Nonetheless, underlying the choice to either use traditional medicine or biomedicine there remains among the majority of individuals a need to prevent complications and disease progression. It is for this reason that although many people voice a preference to use traditional medicine, that in reality the majority of individuals used both biomedicine and traditional medicine. The use of both types of medicine may indicate a potential for further collaboration in the area of diabetes treatment. The following section will outline biomedical attitudes towards collaboration between biomedicine and traditional medicine.

Biomedical Perspectives

The majority of health care professionals were positive about the potential benefits of collaboration between biomedicine and traditional medicine in relation to diabetes treatment. According to John, this collaboration is necessary to engage 'compliance':

"When we're talking about compliance, that is very much a cultural thing and Native healers could play a major role."

In addition to fulfilling a cultural role, Nancy described the potential for therapeutic benefits:

"I see [traditional medicine] as an adjunct. I don't see it as interfering. I think if they could manage this on Indian medicine it would be great, you know. Some people do, thinking again of somebody in another community, who was able to control his blood sugar all together on Indian medicine."

A number of the health care professionals were, however, concerned with the potential effects of herbal medicine. According to Karen:

“Sometimes I have a problem because first of all to start off with it's an unregulated health profession. Some of the treatments I do think work, but some of them aren't measured. The quantity isn't there. We don't know if it's pure, like if we were talking about bark, well if the substance is that you want to get is bark but there's something else in that bark, how do you know that you're just getting what you want. So it's not the pure substance. I'm not confident at all that sometimes what is being used they're fully aware of the side effects and how it interacts with other drugs. That's my main concern. Because in some medicine you just take a drop more and you could drop dead of a heart attack. So how do they measure the quantity. And if I'm taking something where are they looking up the information because there's just no information that they're looking up... I'm really worried about some of the side effects.”

A number of the health care professionals additionally mentioned the perception that traditional healers who were treating diabetes preferred to be the sole provider of health care. Therefore, individuals would have access to either biomedical treatments or traditional treatments, but not both – posing a potential barrier to collaboration.

A certain hesitancy to accept traditional medicine was also mentioned on the part of some biomedical practitioners. According to Geoffrey:

“There are a group of people using traditional approach to diabetes. And some of the physicians will even tell you that there are some medications that will drop blood sugar level. The physicians don't know enough about this medicine and it is sort of throwing a wrench in the works. I don't think the physicians are giving enough credit to this medicine. These effects need to be acknowledged, and some sort of protocol developed because the person in the community is going to use it.”

Summary

It is clear that clients use both biomedicine and traditional medicine to treat diabetes. Nonetheless, there are a number of issues between community members and health care providers that may represent barriers to collaboration. A number of individuals mentioned a lack of trust towards health care practitioners and the motives of the biomedical system in general. Additionally, issues of power and authority were mentioned over the potentially damaging effects of proposed biomedical treatments.

According to health care practitioners there remains a degree of skepticism towards the use of herbal medicine, although most practitioners remain positive about the potential benefits of collaboration. There is sense that health care practitioners perceive traditional medicine as a means to achieve ‘compliance, whose effectiveness is due to cultural rather than therapeutic benefits. This attitude may potentially contribute to a hesitancy on the part of clients - who consider traditional medicine therapeutically effective - to inform health care practitioners that they are using traditional medicine. Another potential barrier to collaboration is the use of diametrically opposed definitions for “medicine”. According to community members, traditional medicine addresses the whole person – specifically, the underlying reason *why* an individual is ill. In contrast, biomedicine emphasizes the

need to get at the “pure substance” and certain health care practitioners described being hesitant about the use of substances that are not pure in treatment.

These issues would have to be addressed in the road towards collaboration. Nonetheless, collaboration represents a desirable goal on the part of *both* community members and health care practitioners. The following section will specifically explore the medical management of diabetes.

Diabetes Management

First Nation’s Perspectives

Among the individuals who have diabetes the majority stated that they ‘closely’ manage their diabetes. When asked what motivates them to closely manage their diabetes, individuals mentioned both the fear of having to use needles, and also the fear of secondary complications. Annie mentioned this fear coupled with the realization that diabetes was a chronic disease:

“I thought a couple of pills and it’ll go away in a week or so. [The doctor] said you’ll have it for life. First comes the pills he said and then comes the needles. Well they said the magic word.”

Dennis described what his reaction would be to having to take insulin:

“I try to follow up to the best of my ability. Before I wasn’t taking any pills for it. But it got out of hand and I had to settle for pills. And the next round will be the insulin. I told the doctor if it’s going to come to that, forget it, I said.”

A fear of the secondary complications of diabetes was also mentioned in discussions of diabetes management. Margaret discussed these fears:

“I worry about the complications, going blind. But I try not to think about them. It causes stress if you worry too much. Worrying about your blood sugar that causes stress...I didn’t want to end up with losing your feet and eyesight and all that. I figured if I followed the diet and stuff that I wouldn’t get to that point.”

Most of the respondents articulated that close management of diabetes would prevent secondary complications or having to use needles. David discussed this perspective:

“Those fears of getting beyond those limits sometimes scare me. What could happen if I go there, if I go too low or too high. But if we keep really looking after everything you shouldn’t have to have that worry.”

As a corollary to this perspective is a sense of individual blame and responsibility if the disease progresses to the point where insulin injections are required or secondary complications occur. This sense of individual responsibility was evident when Doris discussed her brother:

"When he got it he said "I'm going to exercise, I'm going to do all this." And he did. And then after awhile, he went back to his old habits. And now he's dependent on needles. See he could have prevented from going to the next step, but he didn't. So you can prevent it from going to the next step. But no he went back to the old habits. I said, gosh, it kind of makes you angry. Why do you do this when you could have prevented it?"

Most of the respondents were aware of the potential consequences of not managing their diabetes and articulated a corresponding desire to prevent them. Additionally, a sense of individual blame existed surrounding disease progression. The following section will explore the perceptions of health care providers surrounding client management of diabetes.

Biomedical Perspectives

John described medical management as the following:

"Diabetes management, to me, is monitoring patients for complications and ensuring their blood sugar levels are "normal"."

Expanding upon this definition, William added:

"Diabetes management, normally, I think would mean striking up some kind of therapeutic relationship in which you try to educate people about the disease itself. Hopefully, you engage the system so that they can get information about how they can modify the disease. And then you look towards the long term complications and how you can minimize the risk of those developing. That's what I think of when I think of diabetes management."

Among health care professionals, 11 stated that they consider the medical management of diabetes successful, if clients comply with recommendations. The underlying message is that good management of diabetes will decrease the risk of complications. According to Andrea:

"When it goes uncontrolled then it leads to a lot of complications."

Similarly, William stated that:

"There's a tremendous amount of fear around these complication, and the message doesn't get out that there is a way, probably, to avoid those things."

Nonetheless, as is evident in William's use of the word 'probably', there is also a considerable degree of uncertainty on the part of health care professionals as to the effectiveness of proposed treatment. According to Karen:

"I think [complications] happen anyway in most people. I think you're lessening the time. You don't know if things are going to happen or if they're not going to happen to you, but if you sort of manage your diabetes better then maybe you'll get more quality time out of your life, or maybe it won't happen at all."

John had a similar perspective:

"I put it into a whole package, managing your blood sugar, we expect will minimize your complications. But there is no guarantee. So in five or ten years when people have eye problems they're not surprised by it."

When asked to comment, whether in their experience the medical management of diabetes prevents or delays complications, John had this to say:

"That's our understanding as far as physiology goes, but there have been no signs to prove that's the case. I have diabetics who have poor management, whose blood sugar levels have been high for twenty years who have no complications. That sort of flies in the face of that. I also have patients who are well managed who go on to complications. So monitoring blood sugar is no guarantee."

William's comments resonated with John's:

"We can tell people that their risk of complications is lower if they manage it. The problem is that they see a lot of people managing it but still going on to complications. Half, or not even half manage it. And what we're really talking about when we're talking about preventing complications, we're talking about serious management. It requires a fair bit of effort."

In summary, Connor added:

"We're the cynics capital of the Western hemisphere when it comes to diabetic management."

Summary

In the narratives of community members there is a sense that with proper management individuals will be able to prevent or delay complications. This indicates that there is a high degree of knowledge surrounding diabetes complications and an acceptance of the biomedical position that intensive management will prevent or delay complications. Fear of these complications coupled with the fear of having to take insulin injections is what motivated most community members to closely manage their diabetes. Nonetheless, the stress that results from knowledge of the potential consequences of poor management can contribute to a sense of denial, and may therefore cause certain individuals to ignore the disease.

Within the biomedical narratives, although the rationale for diabetes management is to prevent or delay complications, a number of health care practitioners described an uncertainty over its effectiveness in practice. Several people mentioned that an inability to prevent or delay complications was due to different interpretations of management on the part of clients. That is, good management requires a "fair bit of effort" and according to the health care practitioners this type of management is not taking place in these communities. Therefore different interpretations of diabetes management on the part of community members and health care practitioners may be contributing to treatment barriers. Another possible interpretation is that although community members express a desire to manage their diabetes, they are not

realistically able to do this due to other factors. The following section will outline health care practitioner's perception of the management that is realistically taking place.

Barriers to the 'Management' of Diabetes

When asked to comment on how they approach diabetes management on a day to day basis, William responded:

"What we do a lot of the time is people come in and we say "Gee, your sugar is high today". That's sort of the sum total of management. And that's most unsatisfactory."

When asked to comment on their interaction with clients regarding diabetes management, Connor replied:

"Especially with older First Nations patients, they're real polite and they don't want to cross you and they so "Oh yes, thank you very much and go away and don't do anything". In their interaction with you, they don't want to make you angry. And the clinics over there, they plan around that day. "Well, I've got to get up early, make sure my sugar's OK". And they'll sometimes actually apologize to you, "I completely forgot I was coming today, that's why my sugar's so high....because I wasn't careful this morning like I usually am when I come to see you" (laughs). And that's a real eye opener because when they're careful and they come see you, their sugar is 20 and when they're not careful it's thirty. I mean that's not everybody, but there is this idea that they need to please you, and I say that "you shouldn't be doing it for me"."

Other practitioners, such as Karen, discussed a lack of trust on the part of clients towards the advice given by biomedical practitioners:

"It's kind of hard to explain, but when I have a patient, yes I think of their cultural background, but I do that for every individual patient. So that's always a part of your background. But I don't make a distinction that you're different from me, whereas I'm different. Even things that I tell people that are written in literature, that doesn't matter, because whatever is written isn't as good as what like let's say your elders might have said. Like scientific proof doesn't seem to hold much weight. Maybe again going back to historically, it's the mistrust I think. And here we are, barging in again, changing something totally that people don't really feel they need changing. If they don't feel they need to change this, then they're not going to look at it very favourably."

The above statements describe how cultural barriers and communication barriers may impede successful management. Among the health care professionals, 11 mentioned having difficulty communicating with the client. According to William:

"But I can tell you that in that six years, there is a cluster of people that I've been seeing, once a month or so. It's always the same. There's something about the way I'm interacting with them, something in which they see the disease culturally and I'm not able to communicate effectively my concerns about the disease, or generate interest."

John discussed what he considered to be at the root of these barriers:

“There are cultural barriers, I think mainly because people don’t understand diabetes as a major health problem.”

Among the health care professionals, 13 believed that a lack of compliance with lifestyle changes and denial about the disease prevented clients from effectively managing their diabetes. According to Beth:

“I think they don’t really take diabetes seriously. Until it gets too unmanageable where say they’ve had a leg amputated or foot amputated. But even then, in a lot of those cases, that person still goes on smoking. And I think too when they’re elders they get more set in their ways as to what they’re going to do, and you can’t tell me to do this and all that kind of stuff. And there’s such an avoidance of having to see a doctor too around here. I don’t know. They probably explain all that to the people. But if they have it set in their mind that, I ain’t going to do a damn thing you tell me, that’s kind of what they’ll do. They don’t really put a value on what the doctor or what the diabetes clinic has told them. They’ll just go back to their own lifestyle, what they know, and what they do.”

Many of the health care professionals viewed the existence of denial about the disease as motivated by a lack of acceptance of the recommended lifestyle changes. According to Nancy:

“Well if you have a disease that imposes so many limits on the lifestyle and things you don’t like, then I think it’s sort of normal to deny it.”

Among the health care professionals, 7 discussed the fatalistic attitude on the part of clients as a barrier to effective management. Karen described this attitude:

“I’ve been told that ‘when you get your diabetes, you’ll know what I mean’. And I thought, pardon me? And this is by maybe a 40-year-old saying when I get my diabetes. So I think it’s becoming an accepted way of life almost. And like I thought, well actually I’ve been taking care of myself quite well, I don’t expect to develop diabetes.”

Jane described how this attitude affects client response to treatment:

“I think that part of the problem is that, in many of these families, other family members have had diabetes and it goes past the point of being an illness. It’s almost like a natural part of the aging process. So that the impetus for treating yourself aggressively, it’s not there.”

This idea of normality was repeated in William’s statement:

“Yeah, it’s almost normal when it’s in the family, like “Oh well, she’s diabetic”. Sort of an inevitability about it.”

Geoffrey placed this fatalism in historical context:

"Well, I think that basically a lot of the attitude in First Nation's communities is fatalistic because they haven't had control. It's kind of been zones of oppression in that they haven't been allowed to make decisions. Someone has told them. It goes back to the old health posters that used to be on the walls, "check with your local physician". In FN you didn't do anything without accessing a physician. Because everything was against the law, to have traditional medicines, different ceremonies. So as a result you basically taught a dependency. You took away independence and ability to treat oneself and put that all in the hands of the health care system and the physicians. And then they turn around and say, "Why is everyone running to emerge? Why are FN always running to the doctors office?". Because you told them and trained them not to use anything that you couldn't buy off the shelf. They really disabled individuals in the community."

Among the health care professionals, 11 discussed structural constraints creating barriers to effective management. These structural constraints were mainly considered significant due to their impact on diet. According to Geoffrey:

"A lot of these families are living with minimal income, on welfare so it doesn't go very far. Definitely financial constraints."

Nonetheless, 7 of the respondents stated that they did not consider the lack of money to be an issue. According to Karen:

"I think it's just the choices that people make. You can make bad choices and you can make good choices. If you really wanted to do something I think you'll always find someone to help you. There always seems to be money for other things like cigarettes and booze and bingo. So I don't believe all that."

Several health care workers also discussed the physiological response of the patient as a potential barrier. Specifically, that the proposed treatment actually makes the client feel sick. William explained this phenomenon:

"The other thing is that people's sugar has been thirty for the past six years and you try and push their sugar down and they feel hypoglycemic. So they rush out and grab their glass of orange juice and put in a teaspoon of sugar and ah, then they feel better. So people train themselves to become hypoglycemic, much higher sugar levels than a normal glycemic and you're treating that, and you're making them actually feel these episodes and they think you're all wrong. That's a problem sometimes too. Even in the hospital, we had someone here who was describing the symptoms of hypoglycemia and we rushed along and gave them some sugar. And then afterwards we measured their sugar and it was twelve or something, so he's a person that's regularly in the twenties so we were falsely treating symptoms."

Summary

The narratives of health care providers describing barriers to diabetes management largely attribute poor management practices to a lack of individual motivation. The lack of compliance with lifestyle changes, a sense that the advice provided by health care workers is not valued, an avoidance of doctors and a fatalistic attitude indicate the perception that individual choices on the part of clients are getting in the way of effective management. Communication barriers between health care practitioners and clients is further contributing to poor management. In contrast, narratives of community members indicate that there are practical problems associated with achieving the goals of medical management. Most community members articulated a desire to prevent or delay complications and the progression of diabetes. Therefore, although the knowledge and the will to manage diabetes exist, that certain factors in the everyday lives of those affected are impeding diabetes management. Andrea, a health care practitioner alluded to what some of these issues might be:

“Some of the houses that you’ve been in, the last thing people are concerned with is diabetes. If they have diabetes, they’ve also got ... there’s violence in their life, there’s drugs, there’s alcohol. So those are much bigger issues that people have to deal with.”

The following section will look at barriers from the perspective of community members in order to provide further insight into barriers for management.

Living With Diabetes: Consequences

When asked to discuss difficulties associated with living with diabetes, 16 individuals mentioned economic difficulties. Margaret discussed her own difficulties maintaining the proper diet:

“But you can live with it and have a decent life. But sometimes it’s hard like for us in the middle of the week is our hardest part because we’re both pensioners. We have no source of income to fill the gap between the end and the first of the month. So when you run out of, I try and buy enough to last from month to month, but then something always happens... we don’t always have those four things that you need to have in a meal.”

Gregory outlined these same problems:

“Yea. I think for one thing is not eating properly. Not having the right foods for your system. I mean you have to have all kinds of vegetables. A lot of people can’t afford these things. They just eat potatoes dipped in grease. Some people just don’t have the funds. A lot of people that have jobs, they can afford stuff, but a lot of people don’t. And then you don’t have a job. You’re living from one welfare day to the next. And that’s stressful. Nobody wants to be on welfare. Everybody wants to work. But a small reserve like this, there’s no work. Only certain people work and the rest of us have to sit around... They have health clinics but when you go home, what are you going to eat? This is what you’re supposed to eat. Well, hey listen, I’ve only got so much in my welfare cheque and I can’t afford all this fancy stuff.”

Nonetheless, when asked to discuss the consequences of diabetes, 5 individuals explicitly mentioned that they do not feel that there is a lack of money. According to Sylvia:

“Oh I think they can, it’s just that they don’t put out the money because they want to get this. So material. I really believe people here or any community can really afford what they want to get. But groceries, their grocery list goes down even more, and they don’t get what they should get.”

Despite a discussion of structural factors as a consequence of being diagnosed with diabetes, for many individuals, the emotional consequences of being diagnosed with a chronic disease were most significant. Following diagnosis, a number of individuals mentioned feeling a sense of anger. Eugene mentioned his first trip to a grocery store following his diagnosis:

“Yea rage. I stopped at the store on the way home from the hospital and aisle after aisle of stuff I perceived I couldn’t eat. I thought there’s nothing left for me here.”

David described his feelings:

“Terrible inside. Well kind of resentful. I do all this stuff like say ok I’ll quit drinking, become a better person, right? And here is what my reward is— what the diabetes? Come on man, if there’s a God up there, when I get up there, I’ll kick his ass. That’s how I felt. I felt really, really angry. Disappointed. Sad. Resentful. Just a lot of different things. All negative mostly because look man what the hell, I’m doing all this, and this is how you repay me, fucker. I don’t know, I was really, really angry.”

In addition, David described a sense of shame at being diagnosed at such a young age:

“Yea I’m ashamed of it. I don’t want to have it. I only thought it would be someone’s disease like when they’re 50. To affect someone as young as me, it just sucks.”

Despite the disruption in his life that Gregory felt following his diagnosis he also described how he chose to deal with these consequences:

“I thought, well damn I won’t be able to do normal things again. Then I thought to myself, what is so normal of what you’re doing. It was abnormal of what you were doing. And now go back and do normal things and you may be alright for ... at least you can live without any problems. And the doctor told me, he said, the sooner you realize that you have diabetes for the rest of your life, then accept it, it will be easier for you to have. So one day I said, I got it, I got it, and I’m going to take this needle every day so that’s it. I don’t worry about it any more. I don’t worry about tomorrow. Tomorrow is not here yet.”

Denial as a response to being diagnosed with diabetes was mentioned by most respondents. Raymond defined what he meant by denial:

"I go a lot of days without thinking about it. I take my medication, block out that I have diabetes. Sometimes I think about it. When I go to see the doctor, that's mainly when I think about it. Sometimes if I wait too long for a meal or a snack I get the shakes, then I think about it."

When asked to characterize this denial, Annie responded:

"It means I wish I never had it. Or why is it me? Then I have bad days. Then I have good days. But I try and not think about it. If I have a sore toe, I panic because I don't want my foot cut off. And I've seen so much of that. You hear so much about it. It's just what would I do, what would happen... I lose my arm or gangrene this, this, this nonsense. Not nonsense, but this should happen because it all goes back to diabetes. Everything. Everything goes back to diabetes."

For Margaret, the inclination to ignore diabetes is due to the lifestyle changes required:

"I think their diet, of what they're supposed to eat. I think that's why I denied it. I had to go on this special diet. I didn't know there was meals out there you can have that aren't as bland as years ago."

Extending from this need to make lifestyle changes, Gregory discussed not wanting other people to know:

"So if you're doing something you shouldn't be doing, people will come and tell you, hey you've got diabetes, you shouldn't be doing that. So you don't like people telling you all the time. You know what it is. You don't have to be reminded. So you just don't say anything. You keep it to yourself and hope nobody finds out".

Additionally, Gloria mentioned a resistance at being labeled 'sick':

"I think there's denial around a lot of things because everybody's Indians don't get that, Indians don't get that. That we're curable for everything. That there is nothing wrong with us. This is how you are type of thing... They don't like the label I guess. I don't know."

Summary

The impact of financial constraints is outlined as both a consequence of diabetes and a potential barrier to management. A discussion of the emotional consequences of living with diabetes further illuminates barriers to management. It is apparent that although a desire to manage diabetes exists, coupled with a high degree of awareness of the potential repercussions of not managing diabetes, achieving effective management is difficult in part due to the emotional consequences of the disease. Specifically, that the emotional reaction at the time of diagnosis is significant and can result in a sense of despair about the disease and its inevitable progression. There is also a sense that individuals do not want to be identified as having diabetes in part because they do not want their lifestyle choices to be placed under the

scrutiny of other individuals. As such, various levels of denial exist surrounding diabetes and its management.

Knowledge of Diabetes

Prevention

Among those who did not have diabetes, 7 out of 13 individuals were concerned with the possibility of developing diabetes in the future. Four of these individuals have immediate family members who have diabetes and therefore this concern may be related to a perception of risk associated with genetic predisposition. For some, this concern was motivated by an awareness of secondary complications. In contrast, 6 out of 13 individuals were not concerned about developing diabetes in the future. Only one of these individuals had family members who had diabetes. Sylvia, a 23 year old woman, was not concerned due to a perception of the effects of the disease itself:

“They’re still looking for a cure. But I’m glad there is something to control it. I mean there’s probably some things that do control it but it’s not going to kill you. It’s not a real bad disease that’s like just eating away at your body or anything that you’re going to die from.”

Related to a concern about developing diabetes is the issue of prevention. Whether or not diabetes is preventable closely relates to perception of cause: the two poles of which are genetic causes (not preventable) and lifestyle causes (theoretically preventable). Among those interviewed, 18 considered diabetes preventable. Among individuals with diabetes, 7 individuals considered the disease preventable. In contrast, 11 of the individuals without diabetes considered the disease to be preventable. In this sense, discussion of prevention closely relates to a sense of personal responsibility for the illness. Dorothy described this sentiment:

“Yea. That’s what I’m saying. Like they check me all the time and I don’t have it. But what if they say to me, Dorothy you have it. Well then that means I’m not in control, I haven’t taken care of myself properly then. And you’re the only one that can do that.”

The guilt that is associated with not pursuing a lifestyle that can potentially prevent diabetes may explain the discrepancies between individuals with and without diabetes. That is, individuals with diabetes may resist placing blame for the onset of diabetes on themselves in order to minimize a corresponding sense of guilt.

The attitude that diabetes is not preventable is affiliated with a perception that it is also hereditary. In this sense, perceptions of the cause of diabetes can influence individual actions. According to Jesse:

“Doesn’t matter what you do. That’s what it is I think. If you’re going to get diabetes, you’re going to get diabetes. It’s the same with arthritis.”

Cures

Among the respondents, 12 explicitly mentioned that there is no cure for diabetes. In contrast, 7 individuals mentioned the existence of cures for diabetes. This category refers to situations where people have knowledge of the existence of a cure, or who stated that they know people who have been cured. Discussion of cures was more frequent in Sucker Creek than in Birch Island. For some individuals discussion of a cure refers to taking traditional medicines or making lifestyle changes that enable the individual to stop taking insulin. According to Gloria:

“I’ve heard in some cases where people have gotten cured of diabetes through traditional medicine and stuff like that, but it’s really up to the individual. They could take medicines to help them where they could get off insulin, but they still have to keep that balance in their intake of food and exercise and stuff.”

Nonetheless, for others, such as Rose from Sucker Creek, knowledge of a cure touches on other issues:

“They have got a cure but the FDA won’t pass it. I know that for a fact. Oh, we’ve got a lady up here who’s got diabetes. We were talking about. I asked her why don’t they pass it....She’s got some there that cures diabetes. But she says she hasn’t touched it yet.... she said it comes from Hawaii....But you’ve got to believe that it will cure you. But they said the FDA won’t pass it. The pharmaceuticals they don’t want it. Either that or they’re fighting against it. There’s too much money involved or something....It all has to do with money.”

The majority of the respondents mentioned that there is no cure for diabetes. Nonetheless, the perception that there is a cure and that this cure is being suppressed highlights a lack of trust between certain clients and health care practitioners. Individuals who mentioned the existence of a cure also mentioned a preference to use traditional medicine to treat diabetes. Therefore the perceived lack of motivation on the part of biomedicine to find a cure for diabetes has decreased the trust of a minority of those interviewed in the biomedical system. These individuals may be more inclined to seek alternative treatment.

Future Predictions

Among the respondents, 14 stated that there would be an increase in diabetes in the future. An additional 5 individuals stated that the occurrence of diabetes would continue at the same rate. Gregory stated why:

“I think it’ll increase if anything. Because like I say it’s the stress, the poor eating habits.”

In contrast, 8 individuals articulated that the occurrence of diabetes would diminish in the future. This decreased occurrence was mainly attributed to greater awareness and a change in lifestyle factors. According to David:

"It's hard to say. If everybody gets the awareness and the communication going, it'll be decreased. Start looking back to learning about themselves, family, and stuff. It will decrease if they change their lifestyle."

Among the health care professionals, 5 individuals stated that the occurrence of diabetes will likely decrease whereas 9 individuals explicitly stated that they believe diabetes will remain a problem. According to Michael:

"I think it will always be a problem. How we manage it may improve though."

Summary

According to community members the occurrence of diabetes will likely increase or stay the same. This perception highlights a sense of inevitability surrounding its onset even among individuals who have knowledge of preventative measures. This perception may indicate that these preventative measures are either not considered effective or alternately that they are considered realistically achievable. Similarly, the majority of health care practitioners stated that diabetes will remain a problem. This attitude is rather pessimistic in light of the emphasis among health care practitioners on the role of lifestyle factors (theoretically modifiable) in causation. Nonetheless, it may potentially result in a focus on management rather than prevention in health care initiatives.

Diabetes Information Survey

The following section will outline the results of an information survey conducted as part of "Diabetes Day", which was hosted by the Birch Island Community Health Centre on June 24, 1998. Individuals entering the community centre were asked to fill out an anonymous survey before visiting information booths. The following information is based on the results of 16 responses. In general, the results of this survey support the information gathered from the interviews.

The majority of individuals who completed the survey did not have diabetes. Most of these individuals had family members with diabetes and were also concerned about the potential to develop diabetes. The majority of the individuals surveyed characterized their lives as 'stressful'.

Most of the respondents stated that diabetes is a "big" problem in the community and has been around for the past fifty years. Nonetheless, a number of individuals stated that they believe diabetes has always been a problem. This finding was not supported by the interviews where most people described diabetes as a recent phenomenon. The majority of individuals also in the survey articulated that it is possible to prevent diabetes. Nonetheless, when asked to outline causative factors, the majority of individuals stated that it is genetic and runs in families. Additionally, most of the respondents stated that the occurrence of diabetes will likely increase in the future. In this sense, the assertion that diabetes can be prevented is called into question.

When asked to characterize a healthy body size the majority of individuals chose the statement that a healthy body "has a bit of weight on it" (as opposed to the

statements “has no extra weight on it” or “has a lot of weight on it”). This finding supports the information gathered in the interviews. Additionally, most respondents stated that they would prefer to use a combination of biomedicine and traditional medicine. A number of other respondents stated that they would prefer to exclusively use traditional medicine.

Conclusions

Biomedical Perspectives

Among the health care providers, the majority (16 individuals) emphasized the need for improved education programs and increased intervention. Thirteen of these individuals emphasized the need for an ‘Integrated Approach’, referring to collaboration between traditional medicine and biomedicine. Nine of these individuals advocated what was referred to as ‘Native ownership of the problem’. William described what was meant by ‘ownership’ in his recommendations:

“What would be nice, I think, would be for the community to take on ownership of this disease, or epidemic, or whatever you want to call it. That is, what can we as First Nations do about it? Maybe then people within the community with the disease would say, well, it’s been identified by the community as a problem, so we should take it seriously. Because they don’t take it seriously when I tell them about it.”

First Nations Perspectives

Many individuals emphasized the need to have structures in place to address mental health issues. Through community support systems, it is believed that individuals will be better able to respond to particular illnesses along with increasing the overall health of the community. David outlined what he felt should take precedence:

“A solution for it. There’s so many things. One, the people got to get happy. They ought to start talking and get their shit out. They got to start eating healthier. They got to start becoming aware of more other things like the dangers, the effects of alcohol, food, sugars, everything. But the main thing that would help a lot of people is if they can get rid of bad feelings and stuff and become balanced in their lives. Then they would start living balanced. And then eating balanced. Working out more. Becoming more physically active that way they would maintain their weight and start watching it and stuff before it even affects them. That way they wouldn’t have to worry about having to monitor this. To make them aware that you have to get out there. But then to get everybody to start talking to each other, that’s almost impossible.”

Within David’s statement, improving mental health is at the root of addressing the problem of diabetes. Nonetheless, there is also a sense that addressing mental health issues is ‘almost impossible’ resonating with the sense of inevitability surrounding diabetes previously discussed.

Many people articulated the need for increased education, particularly of the younger generations. Margaret outlined the importance of education for prevention:

"I think what has to happen is, we have to educate the young people so they don't get diabetes, knowing the complications of diabetes before you get it."

Annie outlined the importance of culturally focused education:

"I mean sort of bringing in ... talking more about traditional knowledge, talking more about sort of going back to looking at more a cultural focus to things."

In this last statement education implies 'looking back' at traditional knowledge rather than strictly being educated about the disease.

Gloria outlined the importance of bridging education with day to day practices:

"I think more information to the young people to even the ones that are in school and to their parents especially. It seems you can give the kids all sorts of information. I know my son comes home with tons of information about you know if a guest speaker has gone in and things like this. But if you don't live it, you're not going to learn it. It's just like our language. If you don't live it, you're not going to learn it. So something that might be taught at school, if it's not taught at home, then you know, sorry. The information isn't being practiced."

There is a sense, in this statement, that knowledge must be practiced in order for it be worthwhile.

When asked whether re-incorporating certain traditional dietary practices would be desirable some individuals stated that this would be unfeasible due to pollution. Nonetheless, other individuals see a place for certain elements of the traditional diet in contemporary life. Doris stated:

"We may not be able to go hunting but some traditional where we can at least incorporate it like learning to cook deer, buffalo or whatever. And some people say it's a bitter taste, well there still comes the spices you know. How they do those things, you're cooking in a good way. Maybe we need to go back to that. It's not a hard process. It's an easy process. But you just can't turn on the microwave."

As was previously mentioned, the possibility for collaboration between traditional medicine and western medicine was also emphasized by clients. A number of the younger respondents, such as Dorothy, would like to have access to a combination of approaches:

"Making sure that you're taking [Western medicine] and making sure that you follow it according to their instructions and whatever. But I'm just talking about the traditional aspect has to be there because a lot of these folks are going to do it anyway, I'm just thinking of the elders, but even for a younger person like myself, I just want to learn more about maybe the kind of root that I could take as well if I wanted to or maybe there's a special tea that would work better to lower my sugar or whatever. And I would want to know

that. I would consider taking it. But right now I don't know what that is or whatever."

In sum, Dorothy discussed what she considers to be the necessary foundation to solving the problem of diabetes:

"Well let's find some solutions to it. Let's think positively. When you look at a problem and there's always good and bad to everything, but a lot of times people can be so negative about how they're going to deal with a problem. We're wasting so much energy that way. Why can't we just use all this energy and turn it into something positive and say, this is what we could do here, this could be our solution. Often times people get stuck though into this way of thinking where, "no we'll never be able to get out that." It just brings down the whole momentum and people they just don't even want to take care of the situation after awhile. But I think when we hear, well we're drinking too much, we have diabetes, this is another thing, cancer is coming up for example. Well let's start and try and do something to try and offset it somehow. Do the best we can. Again, getting back to your question, just to try and be as positive as you can and finding solutions."

Summary

Both community members and health care providers mentioned a need for increased education. Nonetheless, for community members education was not confined to specific knowledge about diabetes, but also involved 'looking back' towards cultural knowledge. In view of the perceived relationship between diabetes and processes of change that have affected Aboriginal communities the process of 'looking back' can be considered an important component of future solutions. Nonetheless, certain elements of the past – such as the traditional diet – are not considered feasible solutions in contemporary times. Geoffrey, a health care practitioner described the process of 'looking back' as an integral part of gaining control over health:

"People have got to be empowered in terms of their own abilities to care for themselves. And then they need to be given certain tools. I think we have to give people this ability back, to use simple techniques. And then people will understand that they do have control and responsibility. But you're going to have to deal with resentment first. To recognize that the approach to health care took away people's rights."

Both community members and health care providers also emphasized the importance of collaboration between traditional medicine and biomedicine as the larger process of healing. As a corollary, many community members also discussed improved mental health as an integral component of dealing with diabetes due to the emotional consequences of living with diabetes significant. Additionally, the perceived relationship between the onset of diabetes and stress, unemployment, and poor dietary habits suggests that mental health support should be an integral component of future solutions. The ability to manage diabetes is also effectively impeded by factors associated with mental health - specifically, that diabetes is not a priority when there are other more immediate sources of stress in one's life. These factors may be contributing to the sense of inevitability surrounding both the onset and progression of diabetes. The following section will outline general recommendations that have emerged from the study.

Recommendations

The following recommendations represent suggested guidelines for future health care planning. These guidelines are general considerations, rather than specific directions to take with programming.

- Health care planning should take into consideration client definitions for health. Specifically, health care planning should be based on holistic definitions for health.
- Aboriginal perceptions of causation should be considered in future health care planning. According to community members, diabetes is described as a collective occurrence affecting Aboriginal people, associated with larger processes of change.
- Future planning should also address the impact of these changes, in the form of mental health support or community development, rather than focus on individual lifestyle factors.
- The emotional consequences of being diagnosed with and living with diabetes should be considered potential barriers to both prevention and treatment. Additionally, the emotional consequences associated with the circumstances surrounding diagnosis should be considered.
- Health care planning should contribute towards an environment where both prevention and management of diabetes are considered achievable goals by clients. Within this framework, health promotion would be achieved through an emphasis on community development rather than individual lifestyle choices.
- The potential for fear surrounding diabetes and its associated complications to immobilize rather than inspire individuals to effectively manage diabetes should be considered in future health care planning.
- That consensus be gained over the term “diabetes management” - firstly, among health care providers, and secondly, between health care providers and clients.
- Health care planning should emphasize collaboration between traditional medicine and biomedicine. Additionally, barriers to collaboration should be actively addressed.
- Health care planning should focus on mental health issues and ‘looking back’ towards cultural knowledge as a means to combat the sense of powerlessness surrounding the onset of diabetes.

APPENDIX 3:

LETTER TO POTENTIAL PARTICIPANTS

Diabetes Research Project

May 15, 1998

To Whom it May Concern,

The United Chiefs and Councils of Manitoulin Mnaamodzawin Health Board has recently engaged in a planning project for diabetes care. I would like to request your involvement in research directed towards gaining an understanding of diabetes according to your experiences. These experiences may be as an individual living with diabetes; as an individual potentially at risk for developing diabetes; or as an individual with a family member with diabetes. The information gained from this study will be used by the Sucker Creek / Birch Island Health Centre in developing programs, appropriate for diabetes care in your community. It will also be used for a Master's thesis.

For the study individual interviews will be used. Each interview will be approximately one hour long and will consist of informal discussion. As a participant you can withdraw from the study at any time. You also have the right to refrain from answering specific questions in the interviewing.

Any information that you provide will be treated as confidential. All participants will remain anonymous in the final report.

If you are interested in participating, a meeting will be scheduled through the Community Health Representative.

I look forward to meeting with you.

Sincerely,

Julie Sunday
(Principal Researcher)

APPENDIX 4:

LETTER TO PHYSICIANS



United Chiefs & Councils of Manitoulin Mnaamodzawin Health Services

R.R.#1, Box 133 ■ Little Current ■ ON ■ POP 1KO

Telephone: 705-368-2182

Fax: 705-368-2229

Nursing Office - Fax 705-368-3816

May 27, 1998

To Whom it May Concern,

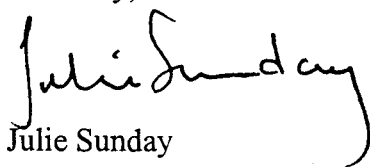
The United Chiefs and Councils of Manitoulin Mnaamodzawin Health Board has recently engaged in a planning project for diabetes care. This research emerges from a partnership between McMaster University and the Health Board. The information gained from the study will be used for future program planning for diabetes as well as contributing to a Master's thesis.

Specifically, the project is directed towards gaining an understanding of meanings, symptoms, causes, cures, and consequences of diabetes. This study has as its focus to develop an understanding of the perceptions and behaviours surrounding NIDDM.

Specifically I will explore perceptions of diabetes from the perspectives of: people with diabetes; people at risk for developing diabetes; and health care professionals. This focus will highlight any divergences in the knowledge surrounding the disease and will help to elicit the relationship between these divergences and attitudes towards treatment and prevention. An additional component of the research will be exploring what type of programs community members have found helpful in relation to NIDDM, and what they would like to see developed in the future.

If you have any further questions please feel free to contact me. I look forward to speaking with you on June 3.

Sincerely,



Julie Sunday

APPENDIX 5:

PROFILE OF PARTICIPANTS

PROFILE OF PARTICIPANTS

A/ COMMUNITY MEMBERS

Whitefish River

Name/ Sex	Age	Diabetic (D) / non-Diabetic (ND)
Raymond (M)	48	ND
Jesse (F)	58	D
Kate (F)	35	ND
Evelyn (F)	55	ND
Mary (F)	26	ND
Donald (M)	55	D
Emily (F)	41	D
Doris (F)	45	ND
Margaret (F)	68	D
Gregory (M)	74	D
Eugene (M)	38	D
Sheryl (F)	36	ND
Annie (F)	55	D
Gloria (F)	45	ND
David (M)	29	D
Rachel (F)	55	D
Gerald (M)	35	D
Dorothy (F)	37	ND

Sucker Creek

Name / Sex	Age	Diabetic (D)/ non-Diabetic (ND)
Dennis (M)	66	D
Cyndy (F)	48	D
Rose (F)	61	D
Jeanette (F)	29	ND
Elaine (F)	45	ND
Sylvia (F)	23	ND
Darlene (F)	39	ND
Bernard (M)	52	D
Helen (F)	45	ND
Robert (M)	52	D

B/ HEALTH CARE PROVIDERS

- 2 Traditional Health Workers
- 2 Dietitians
- 8 Physicians
- 1 Nurse Practitioner
- 3 Nurses
- 2 Community Health Representatives

APPENDIX 6:

PRELIMINARY REPORT

July 16, 1998

Preliminary Findings: *Perceptions of Non-Insulin Dependent Diabetes Mellitus*

Julie Sunday

McMaster University, Institute for Environment and Health

Birch Island

Knowledge surrounding diabetes on Birch Island is quite good. People are generally aware of the disease, its complications, and methods of treatment. Diabetes was identified as a 'problem' in the community by both individuals with diabetes and individuals without diabetes. Nonetheless, concern about preventing or controlling the disease was overshadowed by more immediate concerns, such as mental health issues. Managing diabetes is not a priority when there are more visible sources of stress in one's life. The motivating force behind people who were 'managing' their diabetes well was often fear of having to take needles, or fear of secondary complications.

Perceived causes of diabetes vary, although certain patterns were evident. There is a strong perception that diabetes is hereditary on Birch Island - and therefore not preventable. In this sense, there is a perceived inevitability about the onset of diabetes - that "If it's in the family, you'll probably get it". Changes in the diet, along with stress were also outlined as potential causes. Stress and grief were mentioned as causes of both diabetes and alcoholism. Individuals without diabetes frequently related the disease to the use of alcohol. Additionally, children up to Grade four were found to associate the disease with alcohol use.

Obesity was also mentioned as a potential cause of diabetes. Nonetheless, a 'healthy body' is one that is described by members of the community as having "a bit of weight on it". As one individual described to me, losing weight would be unhealthy for her due to the emotional and mental stress that would result. Another individual mentioned his fear that having diabetes would cause his body to become thin and sickly. Differing perceptions of a "healthy body" by biomedical practitioners and Aboriginal clients may represent a potential communication barrier.

Diagnosis is mainly occurring when people are visiting the doctor for other concerns. As a result there is a certain amount of shock following diagnosis and in some cases resentment about feeling "fine" while simultaneously being diagnosed with a disease. Due to the insidious nature of the disease, denial about the disease following diagnosis exists – most notably with men. The extent of this denial varies between

“just not worrying” about the disease (and therefore not treating it), to not admitting or actively denying that one has been diagnosed with diabetes.

In treating their diabetes, many individuals use a combination of Traditional and Western approaches. Given the choice, most would prefer to manage their diabetes with Traditional Medicine. There is a sense that doctors are not able to spend sufficient time with the clients.

Sucker Creek

There is less specific knowledge about diabetes in Sucker Creek than was found on Birch Island – perhaps a result of there being less diabetes in the community. Similarly to Birch Island, diabetes was identified as a ‘problem’ in the community by both individuals with diabetes and individuals without diabetes. Active diabetes management by individuals was similarly motivated by fear of needles and fear of secondary complications.

There is a perceived relationship between genetics and diabetes in Sucker Creek, although it is not as significant as with Birch Island. The main causative factor mentioned for diabetes was a change in diet – more specifically, the presence of chemicals in the food. There is a sense that processed foods, along with general pollution in the air and water, contribute to ill health and cause diabetes. In this sense, diabetes is considered a relatively recent phenomenon. There are similar perceptions about the effect of body size on health in Sucker Creek as was previously outlined with Birch Island. Most of the individuals without diabetes were not concerned about getting it – as one articulated, “because it doesn’t kill you”.

As was the case with Birch Island, most individuals diagnosed were visiting the doctor for other reasons. Men over age fifty mentioned having several friends whom they suspect have diabetes but who refuse to go to the doctor. Certain individuals also mentioned that they do not believe that there is more diabetes among First Nations than there is among mainstream society – that this is a misconception. They related this misconception to society’s labeling of First Nations people as ‘sick’ and ‘weak’.

In treating their diabetes, many individuals are satisfied with Western medical approaches, although some mentioned using Traditional medicine. Whereas the majority of people on Birch Island articulated an interest in Traditional medicine – in Sucker Creek there was more ambivalence regarding potential treatment. Certain individuals mentioned knowing several people who thought they were cured of diabetes, yet subsequently died. In certain cases the cure was thought to have come

from the church, in others, from Traditional medicine. Two individuals interviewed mentioned knowing about effective cures.

Health Care Workers

Many of the non-native health care workers voiced a certain amount of frustration over what appear to be communication barriers between themselves and the clients. There is a perception on the part of these health care workers that diabetes management is relatively poor among the communities that they are working with. There is a sense that the information they may provide may not be culturally relevant. For this reason, many suggested an integrated approach to diabetes care involving a team of health care workers. There is also a sense that people make efforts to lower their blood sugar levels the day that they have an appointment – rather than managing their diabetes on a regular basis.

Most health care workers attribute the onset of diabetes to poor dietary habits and obesity. Nonetheless, the increase in diabetes that has been observed in the past fifty years is considered to be in part a result of more effective diagnosis. Certain health care workers articulated that many of the lifestyle changes necessary to prevent or manage diabetes effectively may be difficult due to economic constraints. However, the impact of economic constraints on diabetes remains a contentious issue among health care workers.

Although non-native health care workers were on the whole supportive of patients using Traditional medicine, there was some hesitancy voiced over combining Western drugs with other ‘herbal’ medicines. Some individuals mentioned that they would like the community to take ‘ownership’ of the problem of diabetes.

Needs

- To focus on diabetes as a community development issue.
- To recognize that addressing emotional and mental health is a necessary component of both preventing and coping with the disease.
- To develop an integrated approach involving both Biomedical and First Nations Health Professionals.
- To emphasize prevention in future health programs.

- To develop a forum for people to discuss this issue in the community.
- To develop programs that involve visiting people in their homes on a regular basis.

APPENDIX 7:

APPLICATION FOR ETHICS APPROVAL

McMASTER UNIVERSITY

APPLICATION FOR REVIEW BY PRESIDENT'S COMMITTEE ON ETHICS OF RESEARCH ON HUMAN SUBJECTS

(Please submit form in triplicate. Copies of research proposal/application are not required.)

Date: May 12 / 1998

FACULTY INVESTIGATOR(S)*

DEPARTMENT

TELEPHONE #

JOHN EYLES

GEOGRAPHY

ext 23152

STUDENT INVESTIGATOR(S)

DEPARTMENT

TELEPHONE #

JULIE SUNDAY

GEOGRAPHY

ext 24080

TYPE OF PROJECT (Check one)

Faculty Research

Thesis Research: Ph.D. Master's

Other (Specify) _____

RESEARCH SPONSOR (If applicable)

Institute of Environment & Health

Status of Funding (Check one)

Applied For Held

TITLE OF RESEARCH PROJECT

Title: Aboriginal and Biomedical Perceptions and Behaviours Surrounding Non-Insulin Dependent Diabetes Mellitus (NIDDM) on Manitoulin Island

* In the case of student research, the faculty supervisor assumes this responsibility and should be identified above.

(Please refer to the Human Ethics Guidelines *Research Bulletin*, prior to completion of form.)
(If additional space is required, please continue on page 6 of the form.)

1. SUMMARY OF PROPOSED RESEARCH:

- a) State the purpose of the research in the space provided below.
- b) Describe in detail what will be done to the subject. Append a copy of questionnaire(s) or test instrument(s).
- c) Cite your experience with this kind of research.

General Outline of Proposed Research

In this research I will investigate the meanings, symptoms, causes, cures, and consequences of non- insulin dependent diabetes (NIDDM) from the perspectives of both the aboriginal and biomedical community on Manitoulin Island. This study has as its focus to develop an understanding of the perceptions and behaviours surrounding NIDDM.

Specifically I will explore perceptions of diabetes from the perspectives of: people with diabetes; people at risk for developing diabetes; and health care professionals. Additionally, I will explore the relationship between the corresponding perceptions of NIDDM and health-seeking behaviour. This focus will highlight any divergences in the knowledge surrounding the disease and will help to elicit the relationship between these divergences and attitudes towards treatment and prevention. An additional component of the research will be exploring what type of programs community members have found helpful in relation to NIDDM, and what they would like to see developed in the future.

Specific objectives to be achieved in the research:

1. To document how the 'problem' of diabetes is defined by the Aboriginal community and the biomedical community.
2. To explore the relationship between perceptions of NIDDM and behaviour towards prevention and treatment.
3. To explore the relationship between community responses to NIDDM and the biomedical system.
4. To explore what types of programs people would like to see developed for NIDDM in the future.

Methods:

Initially I will identify and meet with key members of the community. This initial stage will involve a discussion of the research project with the community. The research will take place over a period of approximately two months. The first stage of the research will involve group interviews of both individuals with diabetes, and individuals at risk for developing diabetes. These group interviews will create an opportunity to observe the interaction of participants in relation to a particular set of topics. I will follow these initial group interviews with individual interviews in order to explore emergent issues in greater depth. These objectives will be explored through the use of unstructured interviews in order to allow people to communicate on their own terms. I will also interview health care professionals working in this area, through a group interview format. The use of group interviews and unstructured interviews will facilitate the documentation of research objectives from the perspectives of the aboriginal and the biomedical community.

(Circle one)

Do any of the procedures involve invasion of the body (e.g. touching, contact, attachment to instruments, withdrawal of specimens)?

YES

NO

Does the study involve the administration of any prescribed or proscribed drugs?

YES

NO

2. SUBJECTS INVOLVED IN THE RESEARCH:

- a) Describe the salient characteristics of subjects — number, age range, sex, institutional affiliation or where located.
- b) Describe how subjects are to be recruited.
- c) Describe the relationship between the investigator(s) and the subject(s).

2.

a) The first stage will be a series of group interviews in the community. Following this initial stage, I plan to interview approximately 30 First Nation's people: 15 of whom will have diabetes; and 15 of whom will be individuals at risk of developing diabetes. It is expected that both age and sex will vary. Additionally group interviews will take place with biomedical practitioners to elicit an understanding of the problem of diabetes.

b) Dates for group interviews will be advertised in the community. Anyone interested in participating will be invited to join, with date and time of the interviews specified. Following these group interviews, the possibility to participate in in-depth individual interviews will be mentioned to participants. All participation will be on a completely voluntary basis.

c) The relationship between the investigator and the subject will be determined by the subject. Participants will be explicitly told that my role is to create an understanding of NIDDM as articulated by them, and that all the information that they provide will be confidential. The investigator will have no authority to demand participation and all participants will be made aware of their right to withdraw from the study at any point.

3. ESTIMATE OF THE RISKS OF THE PROPOSED RESEARCH:

(Circle one)

- a) Do you see any chance that subjects might be harmed in any way?
- b) Do you deceive them in any way?
- c) Are there any physical risks?
- d) Are there any psychological risks? (Might a subject feel demeaned, embarrassed, worried or upset?)
- e) Are there any social risks? (Possible loss of status, privacy, and/or reputation?)

YES / NO
YES / NO
YES / NO
YES / NO
YES / NO

If the answer is **YES** to any of the above, please explain why alternative approaches involving less risk cannot be used. Procedures for reversing reversible harm should be stated.

4. ESTIMATE OF THE BENEFITS OF THE PROPOSED RESEARCH:

- a) What are the proposed benefits to the subjects, the scientific community and/or society that would justify asking subjects to participate?
- b) What inducement is offered to subjects?

4. This research will be beneficial to other aboriginal communities as well as to political organizations in increasing an understanding of the complexities associated with effectively addressing one of the major health issues facing aboriginal communities. The knowledge documented in this study will contribute to bridging gaps in knowledge surrounding aboriginal health, relating specifically to NIDDM. Theoretically, it will explore the social construction of diabetes from the perspectives of the biomedical and the aboriginal community. On a practical level, it will contribute to a knowledge base necessary for the development of community based health programs. No inducements will be offered to subjects.

5. PLAN FOR OBTAINING INFORMED CONSENT:

Please refer to **Instructions for Preparation of Consent Form**, enclosed, prior to completion of this section.

- a) Describe the explanation to be given to subjects before they agree to become participants in the project. For surveys circulated by mail, please attach a copy of the explanatory letter to the subjects.

5.

a) The focus and the objectives of the research will be clearly articulated to those participating. It will be mentioned that this research is supported and funded by the Institute of Environment and Health at McMaster University. Participants will be informed of their freedom to remove themselves from the study at any point, or to refrain from answering questions in the actual interview. Additionally, they will be assured of their anonymity in the reporting of results.

(Circle one)

- b) Are subjects competent to consent? If not, describe the alternate source of consent.
If a minor, describe the procedure to be used.

YES / NO

- c) Do subjects have the right to withdraw at any time during and after the research project?
d) Are subjects to be informed of this right?

YES / NO

If the answer to c and/or d is no, please explain.

- e) What procedures will be followed for subjects who wish to withdraw at any point during or after the study?

e) Initially it will be determined if their request to withdraw is related to a miscommunication of research objectives. If this is not the case, the individual will be thanked for their participation and asked if the data that they have provided can be used in the study. If participants do not want the data used, it will be destroyed.

6. STEPS TO BE TAKEN TO ENSURE CONFIDENTIALITY OF DATA:

(Circle one)

YES / NO

- a) Will the data be treated as confidential?
If yes, explain the steps that will be taken to ensure confidentiality of the data. If no, explain why.

6.

a)

Data gathered will be treated as confidential. Raw data will only be accessible to myself and the members of my supervisory committee (John Eyles and Wayne Warry) at the university. Data will be stored in transcribed format and locked in my office at the university. The final product, the thesis, will be made publicly available. If desired, short community reports will be written and lodged with local participants.

- b) Where will the data be stored, and who will supervise access to the data?

b) Data will be stored in my locked office at the university and access will be supervised by myself.

7. SUBJECT DEBRIEFING:

Will subjects be debriefed at the end of the research project? If yes, explain how this will be done.
If no, explain why not.

YES / NO

7.

Following the interview, the research project will be explained in a more detailed manner to the participants. If participants do not wish for the transcript to be used in the study, all transcripts from the interview will be destroyed. The resulting thesis will be made publicly available and distributed to the community.

SIGNATURE:

Faculty Investigator

Julie Sunday

Student Investigator

Institute for Environment and Health, McMaster University
Consent form for Participation in Research

Title of Project: Aboriginal and Biomedical Perceptions of Non-Insulin Dependent Diabetes Mellitus (NIDDM) on Manitoulin Island.

Principle Investigator: Julie Sunday (905) 525-9140 ext. 24080

I would like to request your involvement in a research project that aims to gain an understanding of meanings, symptoms, causes, cures, and consequences of diabetes. I would like to interview you to obtain a greater depth of understanding of diabetes according to your experiences. These experiences may be as an individual living with diabetes; as an individual potentially at risk for developing diabetes; or as a health care worker.

For the study, both group interviews and individual interviews will be used. Each interview will be approximately one hour long and will consist of informal discussion. As a participant you can withdraw from the study at any time. You also have the right to refrain from answering specific questions in the interviewing.

Any information that you provide will be treated as confidential. All participants will remain anonymous in the final report. Raw data will only be accessible to myself and the members of my supervisory committee at McMaster University.

This research is funded and supported by the Institute for Environment and Health at McMaster University as well as the UCCM and West Bay community health centres. I will be producing a Master's thesis from the research as well as short community reports. On a practical level, the research will contribute to the information necessary for the development of community based health programs.

I confirm that I have explained the nature of the research project to the participant:

(Principal Investigator)

I consent to the participation in the above research and I hereby authorize the investigator to proceed with the interviews:

Name of Participant (print)

Signature

Date (D/M/Y)