

Investigating the Experience of Diabetes Care in a First Nations Community on the Canadian Prairies

BY

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A Thesis
Submitted to the Faculty of Graduate Studies
in Partial Fulfillment of the Requirements
for the Degree of

MASTER OF ARTS

Department of Anthropology
University of Manitoba
Winnipeg, Manitoba

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FACULTY OF GRADUATE STUDIES

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Acknowledgements

I would like to thank all participants for sharing with me their stories, the community steering committee for their commitment and invaluable comments and direction, and the tribal council health authority for their support and participation. I would also like to thank my advisor, Dr. Sharon Bruce, whom I am indebted to for her comments, practical advice, and encouragement, and my committee members Dr. David Stymeist and Dr. Alan Katz for their insight and assistance. Without the help and support of these incredible people, I would not have been able to undertake and complete this research. I am grateful for having had an opportunity to work with a great number of warm, intelligent and passionate people. I have gained a great deal not only intellectually, but also personally, from engaging with these great people. I would also like to thank the Manitoba Health Research Council for funding this project and the J.G. Fletcher Travel Award for funding travel to the community. This research would not have been possible without the kind and generous support of these awards.

Abstract

Type 2 diabetes mellitus is a serious chronic disease that First Nations Canadians are three to five times more likely to develop than people in the general Canadian population. First Nations people with diabetes are also more likely to develop diabetes complications than people with diabetes in the general population. This may in part reflect the quality of care people in some First Nations communities receive. The purpose of this research project was to explore the experience of diabetes care among people with diabetes, their family members, and practitioners in a small, isolated First Nations community on the Canadian prairies who had voiced concern about the diabetes care available to the community. Through participant observation and semi-structured interviews with health care providers, administrators, people with diabetes, and their family members I elicited and explored the opinions and experiences of diabetes care in the community. Applying Kleinman's Explanatory Models theory, I found that people with diabetes and their practitioners varied considerably in their accounts of (1) the role of pharmacological treatment in diabetes, (2) the emotional impact of diabetes, and (3) expectations of the patient-practitioner relationship. According to the Explanatory Models theory these differences can lead to dissatisfaction in care because the different parties fundamentally understand and relate to these areas of care differently, expressing different knowledge and expectations. I also found that factors outside of the clinical encounter such as issues with obtaining referrals, care at a distance, and care in a non First Nations community impacted diabetes care. Thus sharing patients' understandings of diabetes care with physicians in conjunction with addressing structural barriers to care may lead to better diabetes care and may ultimately impact diabetes outcomes.

Chapter 1: Introduction

Type 2 Diabetes Mellitus continues to spread across the globe, pooling disproportionately in indigenous populations undergoing social transition. In Canada First Nations people have 3-5 times the prevalence of diabetes than the general population (Young et al 2000). Type 2 diabetes is a serious chronic disease that is characterized by high blood glucose levels resulting from reduced pancreatic insulin production and/or decreased insulin sensitivity (Bogardus 1996). Diabetes is of great concern to Canada's First Nations people because the number of First Nations people with diabetes is predicted to increase from 6,100 in 1995 to 17,000 in 2015 (Blanchard et al 1998). Diabetes is a serious chronic illness with many complications such as retinopathy, which can lead to blindness, nephropathy or kidney disease, coronary heart disease, stroke, neuropathy, or poor lower limb circulation, which can lead to lower limb amputation. It is imperative that people with diabetes work closely with a health care provider, ideally a team of diabetes health care providers, to manage the disorder. Close monitoring followed by the appropriate care can prevent or minimize diabetes complications (Leslie 1999). In small remote communities with limited health care facilities the quality of care for persons with diabetes is a concern for community health and well-being. One First Nation on the Canadian prairies has expressed concern over the care those with diabetes are receiving and decided to team up with University of Manitoba researchers so together we could explore and understand their concerns and experiences.

Purpose

The purpose of the study was to explore how people with diabetes in a small, isolated First Nations community and their health care providers regard the care they receive.

Objectives

1. To elicit experiences, stories, and understandings from people with diabetes and their health care practitioners on diabetes care available to community members.
2. To understand the perceived barriers to diabetes care in the community.
3. To understand the expectations people with diabetes have of the health care system in terms of diabetes care.

Health Care Provision Background

The administration and responsibility of some health services have been transferred from the federal government to the community. This essentially means that the band and tribal council have control over the daily operation, provision, and management of health services within the community. Public health services such as health education, immunizations, pre-natal programs, and basic health care are available at the local Health Centre. The Health Centre is operated by the community and supported by the tribal council health authority. They have control over the operation, maintenance, and mandate of the Health Centre and are responsible for staff hiring and training. In addition the tribal council health authority provides many non-insured health benefits (health benefits available to registered status Indian and Inuit persons not covered under provincial, territorial, or third party insurance), such as dental care, medical transportation, vision care, and counselling services. This is a service historically provided to status Indians by Health Canada's Medical Services Branch, but

the tribal council health authority has assumed its responsibility. The tribal council health authority manages the budgeting and distribution of these non-insured health benefits to all of its members. Individuals who previously had to directly deal with First Nations Inuit Health Branch (FNIHB) for reimbursement are now provided those services by the tribal council health authority. However FNIHB continues to administer a few non-insured health benefits such as pharmaceutical drugs.

The Health Centre employs a health director, a peer support worker (who works with expecting mothers), a registered nurse (0.7 time), a community health representative (CHR), a medical van driver, a NNADAP (National Native Alcohol and Drug Abuse Program) worker, a worker in charge of the Brighter Futures Initiative and the Building Healthy Communities program, and an administrative assistant. A Community Health Committee comprised of 5 to 6 community members and a representative from the tribal council health authority meets throughout the year to discuss health programs and problems in the community. They influence policy and priorities in the community. Currently no doctors, dentists, or health care workers who are not associated with the band or tribal council health authority enter the community to provide care. Occasionally employees of the tribal council health authority visit the Health Centre to provide specialized services such as helping to develop programs and giving diabetes education presentations and support.

Residents visit the Health Centre for many different health needs. The registered nurse provides public health care, focusing on things such as health education, STD prevention, pre-natal programs, immunizations, and basic health care. Twice a month the Health Centre holds a diabetes clinic. People with diabetes and sometimes their family

members go to the Health Centre in the morning to check their fasting blood sugar, share a healthy breakfast, and discuss any concerns or questions they have about their health. A short information session is given about diabetes care. The topics range from diabetes complications to dietary management. Depending upon the time of year the attendance ranges from 4 to 10 people.

When community members require health care beyond what is available at the Health Centre they travel out of the community. The tribal council health authority provides transportation for health services to its members to help ensure they receive appropriate and accessible health care. The nearest physicians work out of a rural provincial hospital approximately 80 km (45 min) away. Persons who do not have their own transportation can get a ride to the hospital in the medical van which makes 3 to 4 trips to the hospital each weekday and sometimes makes special trips to on the weekends. Up to 11 people can fit in the medical van, but it usually takes 3 – 4 passengers per trip. In the case of an emergency there is an ambulance service in the nearest town, about 10 minutes away. If the medical van is not available and people must find their own transportation and they are reimbursed for gas money. If the medical van is available and people choose to use their own vehicle they are not reimbursed. Transportation via the medical van is provided to the nearest hospital only. If community members wish to seek medical care beyond the nearest hospital they must pay for their own transportation unless they have a referral.

People usually phone ahead to the hospital to make an appointment to see a physician. If it is an urgent matter (or if they don't have a phone), they can go to the

hospital walk-in clinic and wait for the next available physician. Regardless of whether an appointment has been made waits in the hospital are usually 1-2 hours.

Only hospital physicians have the authority to provide referrals. If a patient is referred to a specialist (most specialists are several hundreds of kilometres away in the nearest urban centre), they are either provided with a bus ticket and accommodation in the city or, if they have transportation, they are reimbursed a set amount for their travel.

Chapter 2: Background

Theoretical Orientation

The work is guided by two different theoretical orientations, each concerning a slightly different nuance of the research: the clinical encounter and the web of power relations that exist in the health care system. The first theoretical framework I have used to guide the research is Arthur Kleinman's (1978, 1988) *explanatory models theory*. This framework theorizes how the clinical encounter impacts care, patient satisfaction, and ultimately patient outcomes. Kleinman asserts that all people with a relationship to a particular illness episode – the patient, family members, physicians, nurses, counsellors, etc., have their own individual explanatory model of the sickness. An explanatory model (EM) of a sickness explains any or all of the following: cause, onset of symptoms, course of illness, pathophysiology, and treatment. An actor's EM may vary over time and is a product of a number of variables – including his or her background, experience, education, and social class. As Kleinman (1978:88) puts it, EM's are “historical and socio-political” products. Practitioner EM's are primarily informed by the medical model of disease - each disease has a primary cause that can be tracked, understood, and treated, and that disease has a biological basis which through knowledge and reasoning can be fully understood and treated - but also by personal experience. Patient EM's are informed by the medical model but are also informed by personal knowledge of the sickness and a desire for symptom relief (Kleinman 1978). Since the EM's are based on different knowledge (technical vs. personal) and goals (technical treatment vs. symptom relief and satisfactory explanation) miscommunication and misaligned expectations can result, which may lead to poor care.

Kleinman's model has been used as a framework to help understand why dissatisfaction in diabetes care exists within the study community. Through understanding the differences between the explanatory models of patients and practitioners we may identify and understand any miscommunication and diverging expectations. Diabetes is a frustrating disease to treat for both patients and practitioners (Helseth et al 1999). Through exploring the different narratives, I hope to identify where some of the frustration lies.

The Explanatory Model theory has been criticized for treating the clinical encounter as if it were a vacuum (Lazarus 1988, Taussig 1980). Diabetes care is impacted by more than the EM's of the different players. It is impacted by the power differential between patient and practitioner and by institutional power. A theory of power relations has been developed from Foucault's (1990, 1995) work regarding the dynamics of power and knowledge. Let us first address the issue of power relations between patient and practitioner. According to Foucault (1995), the formation of *expert knowledge* develops power. Those who can claim expert status and therefore knowledge over a particular domain can make truth claims. This translates into relational power, as experts are enabled to dominate discourses and construct truth and knowledge for non-experts. This power over truth enables experts to probe further into their field of expertise, "unveiling" additional knowledge which is then dispersed and made real through discourse. Discourse on diabetes is dominated and directed by experts through the use of a variety of media, such as education pamphlets, the clinical encounter, newspaper and journal articles, and government diabetes initiatives. Medical experts

dominate discourses about the human body, defining the body, disease, and health for a population. Pappas (1990) argues that physician's power can be used positively or negatively. The physician can use his or her power to ensure good treatment or can employ power to use the patient as a source of income, being uninterested in treatment outcomes. This view, although cogent, ignores the finer points of Foucault's theory of power. According to Foucault, the physician's power isn't simply over a patient but through a patient as an extension of the medical institution.

The medical institution asserts power on and through individual bodies through the *anatomo-politics of the body* (Foucault 1990). Patients seeking care are asked to perform a variety of body movements and complete particular tasks. Arriving on time for their appointment; filling out paperwork; and sitting in the waiting room for hours. These activities treat patients as docile bodies, preparing them for the clinical examination where they are quizzed about their eating and exercise patterns, bowel movements, sexual practices, and asked to assume particular positions so they can be touched and examined. These practices teach the patient that they are docile bodies to be understood and guided by the medical institution for the sake of their own health. The physician has the authority to make certain treatment decisions and recommendations. Docile bodies more readily accept such authority.

The physician acts as one of the points of observation of the medical institution. In this way the physician has particular authority and power over medical treatment decisions – what tests are to be done, what medicines prescribed – but also a more insidious power of observation, where the patient is coaxed into docility by a knowledgeable and concerned medical practice. It is not to say that the patient is

completely docile. In fact, patients often resist the impositions, expectations, and prescriptions of practitioners and medical institutions much to the consternation of many health professionals. However these practices work to encourage docility and compliance and impact power relations and the care encounter.

These dynamics of power are not addressed in the explanatory model theory as originally conceived. Patient and practitioner are considered equal actors in negotiating explanatory models of the sickness episode. However the power relations of the actors affect this negotiation, which impacts the type of care sought and distributed. Furthermore the backdrop of the medical institution shapes care. Hospital regulations, medical insurance restrictions, and general care practices (double booking patients and administrative requirements) shape the type of care expected and delivered. The mundane yet detailed bureaucratic procedures hospitals require of patients (filling out forms, presenting the correct paperwork, phoning to confirm appointments) are processes of disciplining bodies. As Gastaldo (1997: 125) observes, “this experience of discipline is reinforced by mechanisms for minor punishment or reward, based on the individual ‘performances’ of the (health system) users”.

Because diabetes care encompasses lifestyle changes, diabetes care and management for health professionals is often synonymous with diabetes education – particularly healthy lifestyle education. Lupton (1995) and Gastaldo (1997) have both critiqued health education and health promotion, applying some of Foucault’s concepts regarding biopower and subjectivity. Lupton (1995) understands health education as a moralistic and value-laden exercise influenced by neo-liberal understandings of our bodies and ourselves. The body is a reflection of one’s ability to master oneself to

maintain discipline and austerity. Through acting on our bodies we are able to transform ourselves “in order to attain a certain state of happiness, purity, wisdom, perfection, or immortality” (Foucault, 1988:18 cited in Lupton 1995:12). It is not a coincidence that as a society we understand the root of much of our ill health as a result of lack of self-discipline and excess. In a time where more choices are available to citizens and consumers than ever before discipline has become an essential attribute. The so-called degeneration of values, authority, morals, law, health, and safety has become a reflection of the degeneration of giant collectives of individuals. These individuals must then individually look within to make changes – positive changes for themselves and their communities. One’s self-practices (smoking status, diet, and sexual conduct) are an outward manifestation of one’s inner state (Lupton 1995; Petersen and Lupton 1996).

The value system associated with the notion of health promotion is linked to mechanisms of bio-power. Bio-power is a concept Foucault (1990, 1995) developed which examines a method where power acts on bodies. The *anatomo-politics of the body*, discussed above, is a form of bio-power that acts on individuals. Another form of bio-power that acts on populations rather than on individuals is *normalization*. Individual subjectivity is developed to control the behaviour of populations through the process of normalization (Gastaldo 1997). Through the normalization of particular acts and behaviours, people are induced to conduct themselves in particular manners (i.e. to quit smoking or lose weight). People are motivated to control and manipulate their activities and bodies not from the threat of punishment but for their own good. As Lupton (1995:10) states:

Individuals are rarely incarcerated or fined for their failure to conform; however they are punished through the mechanisms of self-surveillance,

evoking feelings of guilt, anxiety and repulsion towards the self, as well as the admonitions of their nearest and dearest for 'letting themselves go' or inviting illness.

Biomedicine normalizes through tabulation (weight and height charts, determining "normal" ranges for cholesterol and blood sugar) and through health education. Health education enforces the notion that particular activities are required to achieve health. Through repeating the importance of diet, exercise, blood sugar monitoring, and smoking cessation, diabetes education encourages individuals to turn the gaze inward (Lupton 1995). It is highly unlikely that by encouraging subjectivity health educators are consciously encouraging the anxiety and self-loathing that can accompany it. Health educators too have turned the gaze inward, adopting the notion that healthy bodies are disciplined ones. Since this is the prevailing understanding of health, health educators are trying to help others help themselves.

This critique of diabetes education speaks to the negative impacts and social development of subjectivity, providing a rather negative interpretation of health promotion. It cannot be argued that individual lifestyle choices have no impact on health outcomes. Writers such as Lupton and Gastaldo do not make such claims. They simply call our attention to the fact that health education is not a neutral activity. It is saturated with the values and norms of a neo-liberal society that promotes individualism, responsibility, and the production and care of the self.

Literature Review

Epidemiology

Type 2 diabetes is now an epidemic among Canadian First Nations people (Young et al 2000). Fifty years ago, diabetes was extremely rare among Canadian First Nations populations (Chase 1937). Today, the prevalence of diabetes in First Nations is 3-5 times that of the general Canadian population (Young et al 2000). The incidence of type 2 diabetes in First Nations is escalating so rapidly that it is predicted that the number of First Nations people in Manitoba with diabetes will increase from about 6100 in 1995 to almost 17,000 in 2015 (Blanchard et al 1998). Associated primary health care costs are predicted to increase from \$22.4M in 1995 to \$96.9M in 2015 (Blanchard et al 1998).

Along with higher diabetes prevalence rates First Nations communities experience higher rates of diabetes morbidity and mortality than the general Canadian population (Macaulay et al 1988, Young et al 1985, MacMillan et al 1996). Research has shown that good management and care of diabetes can reduce the risks of complications (Leslie 1999). Regular foot checks have been proven to reduce the risk of lower limb amputation (Patout et al 2000). In addition regular checks for signs of diabetic retinopathy (eye disease) and proactive treatment reduces the risk of blindness (Maberley et al 2003, Early Treatment Diabetic Retinopathy Study Research Group 1985). Disease outcomes are thus strongly related to the quality of diabetes care received.

Considering that disease outcomes are strongly related to treatment, it is troubling that there is much dissatisfaction with the current model of diabetes care. As will be discussed below both health care providers and patients frequently express frustration and dissatisfaction with diabetes management practices and outcomes. The literature reflects

the inadequacy of the current care model, which is founded on patient education, empowerment, and adherence.

Explanatory Models

Diabetes is widely considered a difficult and frustrating disease to treat (Anderson and Funnell 2000, Helseth et al 1999). This frustration both contributes to, and results from, poor physician-patient communication. Loewe and Freeman (2000) argue that much of the conflict between doctors and patients with diabetes stems from the different explanatory models that physicians and patients use to understand the disease. Research in various settings comparing and contrasting patient and provider explanatory models to help understand the patient-provider relationship and identify opportunities for improved care has proved promising.

People with diabetes approach diabetes care and management in a fundamentally different way than practitioners. Patients are pragmatic in their approaches to diabetes management (Hunt, Jordan, Irwin, and Browner 1989, Hunt, Arar and Larme 1998). They view diabetes management as a series of micro-decisions and continually strive to achieve the best possible diabetes management in light of social and economic constraints. Loewe and Freeman (2000) found that physicians, on the other hand, are much more fatalistic in their approach to diabetes management. They consider diabetes management an often-fruitless struggle to avoid the inevitable complications of diabetes. Both locker-room talk and hospital-based medical education contribute to this fatalistic view of diabetes as they focus on the worst manifestations of the disease. To physicians, diabetes must be aggressively controlled or the results will be deadly (Loewe and Freeman 2000). To patients, diabetes must be managed within a set of other personal and

environmental obligations (Hunt, Arar and Larme 1998). This difference between explanatory models creates friction and potentially causes physicians to interpret their patient's reactions as a lack of discipline or commitment to health. This can create conflict and tension between patient and physician, when one party believes the other is not committed and the other party believes that the first does not appreciate the logistical difficulties of diabetes management. In addition the friction arising from conflicting explanatory models may be exacerbated by cultural and communication differences between non-aboriginal health care providers and First Nations patients.

Beyond impacting the physician's interaction with patients with diabetes, the physician's attitudes about diabetes may affect the management decisions they make. Physician compliance to standards of care for diabetes is low (Larme and Pugh 1998). Larme and Pugh (1998) found that physician non-compliance is related to the physician's attitudes and beliefs. Those who doubted the efficacy of diabetes treatment were less compliant than those who had fewer doubts. Weinberger et al (1984) studied the relationship between physician knowledge and beliefs and the glycaemic control their patients achieved. They found that physician beliefs about diabetes and its management and not knowledge predicted the glycaemic control of patients.

Explanatory Models: Control

The physician's pessimistic attitude about diabetes management is mismatched by the optimistic and encouraging tone of the consultation (Loewe et al 1998). Physicians must encourage their patients to take control over their diabetes, convincing them that they can help themselves. Even though they privately acknowledge doubts about the benefits and efficacy of glycaemic control, physicians blame patients for poor diabetes

management (Loewe et al 1998). Physicians are trained to treat and hopefully cure disease and when faced with a difficult to manage chronic illness such as diabetes they become doubtful about how effectively they can control the disease. They thus centre the locus of control on the patient (Rood 1996).

Perhaps the greatest struggle in diabetes management is the struggle over control. Physicians attempt to both exert control over disease management and patient behaviour *and* convince patients that they themselves have control over the disease outcomes. Physicians encourage patients to adopt prescribed lifestyle behaviours, with the understanding that if they can follow specific guidelines, they will be able to control their diabetes (Loewe et al 1998). Physicians adopt a middle ground between:

unilaterally imposing external clinical guidelines on an unaccepting patient and adopting a near fatalistic individual relativism that does not seek to help people change behaviours that can adversely affect their health. (Freeman and Loewe 2000:511-512)

To seek this middle ground, to work with patients to help them choose healthy behaviours, health care providers require patients who are able to exert control over their lives. Many people in Native American communities doubt the ability they have to make choices that will improve their health (Huttlinger et al 1992). Hunt, Pugh and Valenzuela (1998) found that “non-compliant” Mexican-American patients constantly struggle to maintain glycaemic control in a socially, politically, and economically constrained reality. They simply have limited opportunities to make healthy lifestyle choices. Moreover, not all people within the same sub-population have the same degree of self-efficacy. Self-efficacy varies with sex, age, and income (Hunt, Pugh and Valenzuela 1998).

The History of Federal Health Care Provision for First Nations Peoples

Historically federal health care for First Nations peoples in Canada was delivered in conjunction with missionary and colonial aspirations in the wake of infectious epidemics of smallpox and tuberculosis (Kelm, 1998, O'Neil 1986, Browne 2003). Kelm (1998) argues that Aboriginal health and bodies have been formed through the colonizing process, where the bodies of Aboriginal peoples were targeted for assimilation and worked on through programs such as residential schools, the establishment of reserves, and health care delivery. Veiled by a mix of "civilizing" and "humanitarian" rhetoric the Canadian federal government sought to control, civilize, and make dependent Aboriginal bodies. Missionaries and government officials believed that "First Nations could be brought under control through surveillance, scientific study, and medical intervention" (Kelm 1998:103). Since the colonizers were the superior race it was their duty to govern, instruct, and aid the original inhabitants of Canada. The provision of health care for Aboriginal people was led by the assumption that they could not "care for or manage their own bodies" and that they lacked effective indigenous healing methods (Kelm 1998:151).

This was the beginning of the "dependency" relationship between the federal Medical Services Branch and Aboriginal peoples. A health care program aimed at civilizing bodies combined with a loss of Aboriginal autonomy fostered this relationship. As Browne (2003) writes:

The loss of power and control over most aspects of community life, and the profound decline in health status, paved the way for dependency on health care and other forms of government aid.

The colonial power has fostered this dependency in order to assume and defend control over Aboriginal health. However this presumption over the control over Aboriginal health has always been and continues to be contested and challenged by Aboriginal communities (Kelm 1998).

First Nation's Encounters with Mainstream Health Care Professionals

For many rural First Nations people, a significant majority of their encounters with non-natives are through interactions with health care professionals. These interactions are affected by power-relations occurring within the neo-colonial context of Canada (Browne 2003). Several research projects have been undertaken to examine First Nation people's experience interacting with non-Aboriginal health care professionals. Browne, Fiske and Thomas (2000) found that female residents of a Carrier First Nation reserve in interior British Columbia experienced both "invalidating" and "affirming" encounters with non-Aboriginal health professionals. In invalidating encounters First Nations women were dismissed, subjected to negative racial stereotyping, and felt marginalized and unwelcome in the hospital environment. In addition their personal circumstances such as lack of phone, transportation, and childcare, were often ignored or not considered. As such, they were often penalized for late arrival for a medical appointment. In affirming encounters First Nations women felt that they were active participants in their own health care, genuinely cared for, and their culture and history respected.

In her interviews with First Nations people in a Dakota community in rural Manitoba Shirley-Spiers (1989) found that patients described seeking health care in a nearby non-Aboriginal community as a very difficult and harmful experience. Doctors

and nurses often blamed them for their health problems, or actually dismissed their health concerns and accused them of “taking advantage of the system”. They were the victims of racist remarks and substandard treatment. They expressed their desire to be “treated like everybody else”. In fact they rarely felt as though they were treated like everybody else and their encounters with the health care system were simply a “reinforcement of their subordinate status” (Shirley-Spiers 1998:42). Shirley-Spiers (1989:48) concludes:

The impact of stereotyping and stigmatization is especially pernicious when found within the realm of health care, for it not only leads to overt acts of discrimination, but it also exacerbates the social distance between Native patient and health professional, thereby reducing communication and patient satisfaction. Moreover, the efficacy of medical treatment becomes suspect under these circumstances.

O’Neil (1989) studied the interaction between Inuit patients and non-native practitioners. He found that many of the broader social issues patients attributed to health were either not translated properly by the translator because they did not know how to translate the concepts properly without explaining Inuit concepts of health and society, which they were discouraged from doing, or in other cases the concepts were translated properly but ignored. The medical personnel determined what information was salient to health and what was extraneous. Medical personnel showed little interest in Inuit stories about class differences and alienation. They were comfortable with Inuit stories of difference based on of culture but not politics. O’Neil (1989) concludes that medical personnel fail to appreciate the historical location of western medicine and how the medical institution brackets patient-provider relationships.

Medical institutions are powerful symbols of a recent colonial past. In this context, seemingly innocuous behaviour is often considered by patients as racist. (O’Neil 1989:341)

O'Neil (1989) concludes that barriers to communication include failure on the part of health care practitioners to recognize (1) the socio-political implications of health in the north and (2) that medical institutions continue to symbolize white domination.

Baker and Daigle (2000) investigated hospital care as experienced by Mi'kmaq clients in New Brunswick. These patients indicated that they were often misunderstood and stereotyped because they were primarily perceived as "natives" rather than as individuals. They also found being in the hospital very lonely and isolating. They attempted to minimize the number of negative encounters with hospital staff by "giving no trouble". In addition, many people spoke of the cultural misunderstandings between staff and Mi'kmaq patients, which lead to tension and dissatisfaction for both parties. These included conflict over visiting hours, the number of allowed visitors, and the disciplining of children.

Critique of Culture As a Barrier

Whether inequalities in First Nations health are due to cultural communication barriers or not is debatable. Cross-cultural nursing education has become popular in recent years (Culley 1996). The philosophy behind this movement is that cultural differences in how health and health care is understood, felt, and communicated create barriers to effective and meaningful care. The poorer health status of Canadian First Nations people has been partly attributed to the absence of culturally relevant care. Thus teaching health care professionals about First Nations' health practices, food choices, and communication methods is said to improve care and ultimately the health status of First Nations people. While this is in part true, researchers (Culley 1996, Meleis and Im 1999, Browne 2003) have contested these claims, saying that discussions around culture and the

cultural barriers to health care distract people from the most powerful determinants of health disparities – socio-economic, racial, and political inequalities. As Culley (1996:565) remarks:

Essentially the problems facing minority ethnic groups are reduced to cultural insensitivity on the part of health professionals.

Neo-colonial relations impact both the wider determinants of health for First Nations people – poor housing, poverty, low educational attainment - and the attitudes and assumptions of health care professionals. Cultural awareness training is directed towards overcoming prejudice and ignorance on the part of non-Aboriginal health care professionals. However this approach ignores wider social ideas and norms and assumes that racist attitudes and behaviours are essentially rational, individual choices.

The idea of the ‘prejudiced individual health worker’ tends to neglect the ways in which racism is embedded in structures and institutions. (Culley 1996:568)

In Canada many of the attitudes and assumptions about the health and bodies of First Nations people are historically grounded in the “humanitarian” approach to First Nations health and the development of First Nations’ state dependency. This relationship birthed new attitudes and opinions about the fairness and equity of the “special relationship” between the Federal Government and First Nations people and the capabilities of First Nations people. Within health care as within the wider society, First Nations people’s health has been jeopardized, not simply by a lack of cultural awareness, but also by a lack of socio-political awareness. As Meleis and Im (1999:96) write:

Cultural knowledge without attention to structural/political/positional constraints and without adopting some universal humanistic values is marginalizing. It is not the culture that shapes the healthcare experiences of clients. It is the extent to which they are stereotyped, rendered voiceless,

silenced, not taken seriously, peripheralized, homogenized, ignored, dehumanized and ordered around.

According to this view, attempting to understand not only cultural differences but also socio-economic and political barriers to health and health care will improve client-practitioner relations and satisfaction.

Explanatory Models of Diabetes and Health Among Canadian Aboriginal People

Interesting research has been done to specifically explore First Nations' groups' explanatory models of diabetes. The purpose of this research has been to add to the biomedical-dominated discourse about the etiology and knowledge of diabetes in aboriginal populations. Not surprisingly, aboriginal communities vary in their understandings and evaluations of the causes and meanings of diabetes in their communities. Bruyere and Garro (2000) found that the people they interviewed in a Cree community in Manitoba spoke of diabetes as a foreign entity that sneaks up on people like a hunter tracking prey. Once diabetes has entered the body it travels through the body trying to get out and causing sickness to the area it has travelled to. That is how, as this Cree community believes, diabetes attacks so many different parts of the body. Bruyere and Garro (2000) interpreted this understanding as an indication that community members did not think that individuals could always control diabetes. Diabetes can stalk and eventually overtake its victims. The researchers also found that people associated the onset of diabetes with a discontinuation of the consumption of traditional foods and the maintenance of traditional ways. Thus for them diabetes is closely related to social changes that have been forced on aboriginal communities.

Gregory and associates (1999) interviewed urban aboriginal people living with type 2 diabetes in Winnipeg, Manitoba. Like those in Bruyere and Garro's (2000) study

the people interviewed spoke of the inevitable consequences of diabetes. However much of the discourse was based not on an understanding of the way the disease itself worked but on personal observation. Participants spoke of the slow decline and eventual death from diabetes in many of their friends and family members. They spoke of the consistent and brutal debilitation caused by diabetes. Gregory and associates (1999) observed that patient's understanding of diabetes as an essentially uncontrollable disease contrasted with the advice given by health care professionals to take responsibility and control of their diabetes putting patients in a frustrating and difficult position which resulted in self-blame for not being able to control a disease that fundamentally they did not believe was controllable.

Although many aboriginal people see diabetes as a disease that is uncontrollable once diagnosed there is less agreement regarding what causes diabetes. Garro (1995) interviewed people in an Anishinaabe community in Manitoba about what causes diabetes. She found that community members disagreed about whether it was caused by larger societal factors – the disappearance of wild meat and the addition of chemicals and preservatives to foods – or individual lifestyle choices (1995). Most community members were aware of the two opposing arguments and tended to be swayed by one side or the other. The role of heredity in causing diabetes was not considered to be as much of a factor for community members although many observed or believed that it runs in families. In this case, community members vary in the degree to which they accept and incorporate the biomedical view (a combination of lifestyle and hereditary factors) into their understanding of diabetes.

Gittelsohn and associates (1996) investigated the local understandings of diabetes in an Ojibway-Cree community in northern Ontario. They interviewed several community members about the causes and treatment for type 2 diabetes. Many of the people they spoke with linked diabetes to the consumption of too many “white man’s” foods and not enough “bush” foods. For them, eating too many sugary, salty, prepared, and preserved foods and not enough fresh foods from the bush creates an imbalance in the body that increases blood sugar and eventually causes diabetes. People also believed that stressful life events triggered the development of diabetes. The best treatment for diabetes according to most informants was to increase the consumption of “bush foods” and decrease the consumption of “white man’s” foods. However people did voice concern over the reduced availability of “bush foods” and the relative ease of obtaining high sugar, fat, and salt containing foods at the local Northern Store.

Abonyi (2001) explored the landscape of diabetes in the Cree community of Moose Factory, Ontario. She found that when asking community members about why diabetes has developed as a problem for them, they responded by discussing first the wider social and political changes within the community and the loss of tradition and cultural identity. Physical illness was for many people a manifestation of underlying social, cultural, and economic issues. Diabetes for them was linked to not caring about oneself and self-loathing, which was then linked to “low cultural esteem, or a lack of cultural identity” (Abonyi 2001:146). According to many of Abonyi’s informants, diabetes could only be improved by improving the underlying social, political, and economic conditions that plagued their community. For many community members, such changes required improvements in cultural esteem and cultural identity.

To appreciate how diabetes is often understood in terms of wider social issues, an understanding of different aboriginal concepts of health is useful. Turton (1997) found that the Ojibway people living in the Great Lakes region understood health as a state where one's social and spiritual relationships were in good accord and one was living "as they should". "Living the good life" involved partaking in socially valued activities (remaining connected to the land, being industrious, and "living the Indian way") and avoiding those activities that were not valued (drinking and abusing others). A state of health was by definition one in which an individual was enhancing community relationships and maintaining "the Indian way". Health is thus linked to community and tradition.

Adelson (1998) found a slightly different understanding of health in the Cree community she visited in Manitoba. The Cree translation for health is "being alive well". This state is one in which an individual is living in harmony with nature and living well off of the land, which includes engaging in a variety of traditional activities, harvesting and eating traditional foods, and passing that knowledge to the next generation. Adelson (1998) suggests that the maintenance of traditional Cree subsistence methods is a requirement of "being alive well" and the forced settlement of Cree people is a profound obstacle to "being alive well". In this way community health is directly related to larger social changes.

Garro (1990), conducting research in a Manitoba Anishinaabe community, also found that some sicknesses were conceived of in terms of wider social circumstances. The people she interviewed thought of disease in terms of three separate categories. "*Inaapine*" are common ailments such as colds that can happen for no apparent reason,

“*Anishinaabe* sickness” are conditions that are attributed supernatural causes, often ailments such as colic, palsy, and unusual social behaviour; and “White man’s sickness” which are foreign diseases considered to have accompanied colonization, such as measles, cancer and diabetes. It is important to note that there was no consensus among community members regarding which conditions fell into which categories. However diabetes was commonly considered a white man’s sickness connected to wider circumstances and social relations and not only individual lifestyles and choices.

Huttlinger and colleagues (1992) working with Navajo in Arizona found that people there also considered diabetes a “white man’s disease” and a symbol of “white man’s” encroachment on their land and the slow decline of traditions and culture as a result of “white” encroachment and cultural domination.

Critique of Explanatory Models

Much of the research on aboriginals with diabetes has focused on aboriginal understandings of diabetes. This work is rich and fascinating, but as Lazarus (1988: 43-44) notes understanding a patient’s explanatory model does little to improve or understand the clinical encounter.

Basically, the explanatory models approach defined models so fluidly and so broadly that finding the patient’s explanatory models becomes an end in itself. Explanatory models do not tell us enough about interactions. The approach essentially limits the study of the doctor-patient relationship to a meaning-centered approach. It focuses mainly on the health and illness beliefs of individuals, and not on the doctor-patient interaction itself.

According to this critique the explanatory models approach is not a tool with which to understand the dynamic between the patient and practitioner. It is a tool to contrast the different approaches but can only be used to infer communication barriers and misunderstandings that may impede care. Lazarus (1988) encourages researchers to

move their gaze from explanatory models to the social organization of medicine and the impact of the clinical setting, operation, and administration on the clinical visit. Patient-practitioner encounters are framed within the health care system, which is a development of both a biomedical model of health and a neo-liberal model of health care. She claims that modern health care is based on the deployment of expert knowledge, the triumph of modern medicine, the categorization and departmentalization of illness and healing, nicely encased in modern notions of personal responsibility. Considering that explanatory models are “tied to specific systems of knowledge and values centred in the different sectors and sub-sectors of the health care system... and are historical and socio-political products” (Kleinman 1978:88), it is logical to look beyond the explanatory model and tie it to the historical and socio-political setting. Pelto and Pelto (1997) also implore researchers to consider economic, political, and material factors in conjunction with explanatory models when trying to understand illness behaviours. Considering the knowledge and values of aboriginal communities may greatly differ from those of health care institutions, turning our gaze on how people with diabetes understand and react to these differences may provide considerable insight.

The Clinical Encounter

The perspectives of physicians and their relationships with aboriginal patients have also been explored to understand and overcome the barriers to patient-practitioner communication. Kelly (2002) interviewed 10 non-aboriginal physicians who worked primarily with native patients and asked them to describe the communication strategies they use with aboriginal patients. Physicians noted the importance of using culturally appropriate communication techniques, such as speaking less, taking more time with

patients, and allowing for silences. In addition they spoke of the importance of understanding patients' health within their community's context and values. They also spoke of the negative impact of physician turnover. According to them, physicians can only develop relationships, trust, and learn appropriate communication styles to be able to place people's health and wellness within a cultural and social context given time.

Bartz (1999) studied clinical encounters between a non-aboriginal physician and aboriginal patients to examine differences in communication styles and potential barriers to communication. The physician in the study was an experienced family practitioner in an urban Native American health centre who used a sophisticated biopsychosocial approach in her practice and was committed to providing culturally appropriate care. In this study, the physician tried to understand the patient's model of illness and then adapt it to her own understanding of the disease and its care. This is akin to "negotiating" physician-patient explanatory models. Interestingly, this method resulted in an unbridgeable gap in communication, blocked by mistrust and strain. Bartz (1999) attributes the gap in communication partly to the difficulty physicians have with interpreting their patient's stories, regardless of their good intentions.

Following Lifestyle Recommendations

Not only is type 2 diabetes more prevalent in First Nations communities, it is also more difficult for people with diabetes to follow a strict self-care regimen in many of these communities. Fresh produce is not readily available, and when available, it is prohibitively expensive. Exercise routines are difficult to maintain because access to recreational facilities is limited. Moreover, the exercise of self-discipline and self-management may be a lower priority than many of the daily concerns people face such as

poverty, violence, and racism. Limited adherence to recommended diet and exercise is reflected in the disproportionately high rates of diabetes complications, such as end stage renal disease (MacMillan et al 1996) and retinopathy (Ross and Fick 1991) recorded in many First Nations communities. This makes the need for a different model of diabetes care especially critical in First Nations communities.

The issue of following lifestyle guidelines recommended for diabetes has been termed “compliance” or “adherence”. Much work has been done to understand how compliance can be increased. There is an abundance of research that focuses on how particular attributes of persons with diabetes encourage or discourage compliance. These approaches generally consider compliance an outcome of patient psychology and cognitive orientation (Duran et al 1995, Ciechanowski et al 2001). These studies attempt to understand people’s self-care behaviour as a function of personal psychological traits such as “self-efficacy”. Self-efficacy is one’s ability to carry out “health-relevant” behaviour (Rose et al 2002). Another psychological measure that is used to measure an individual’s capacity for self-care is “locus of control”. Individuals with an internal locus of control believe that their behaviours can positively impact their course of illness and those with an external locus of control believe that health outcomes are due to chance (Reynaert et al 1995). According to Peyrot and Rubin (1994), people with an external locus of control should be targeted for education, presumably to educate them to adopt an internal locus of control. Oomen and colleagues (1999) suggest that concepts such as self-efficacy and internal locus of control are not cross-cultural concepts and may not be applicable in all settings. Lupton (1995) argues that the compliance discourse is based on neo-liberal attitudes of personal responsibility and choice. These attitudes are prevalent

in the general population but not as salient in First Nations communities. Moreover, Goodall and Halford (1991:1) in their critical review of diabetes self-management assert that

Trait variables (e.g., personality and demographics) have been presumed to affect self-management, but evidence suggests they have little impact. The important determinants of self-management are transient situational factors such as psychological stress and social pressure to eat.

According to this perspective not only is the dogma of self-control and the science of understanding why some cannot monitor themselves culture-bound, but it also perhaps barking up the wrong tree. “Compliance” is not simply a matter of personal choice per se, but related to environmental stress and pressure.

Diabetes Care Among First Nations

There is virtually no literature on diabetes-related care patterns among First Nations people. The existing literature on care patterns among First Nations people is scant and not directly related to diabetes care. Thouez, Foggin and Rannou (1990) investigated the barriers to health care among the Inuit and Cree of Northern Quebec. They observed that a negative attitude regarding relationships with health-care personnel was a barrier to health care for these populations. In a similar study Schmidt (2000) investigated the barriers to recovery for psychiatric patients in a First Nations community in northern British Columbia. With regard to the quality of health care provided to psychiatric outpatients, Schmidt (2000:80) observed, “because of higher rates of staff turnover in remote areas, it is difficult to develop and maintain reliable, up-to-date, and knowledgeable ... resources in those communities”.

According to these studies Canadian First Nations people’s access to good quality health care is limited by both the patient-practitioner relationship and human resource

issues common to many remote communities. Patient-practitioner interaction may be particularly salient in diabetes care and treatment. It has been noted that, “outcomes of diabetes care may be particularly sensitive to characteristics of the doctor-patient relationship and physicians’ approach to management” (Helseth et al 1999:37). As Dietrich (1996:13) argues, “the reaction and attitude physicians displayed toward the patients at the point of diagnosis were crucial in influencing attitudes towards [diabetes]”. This project aims to add to the literature on both diabetes-related care patterns among First Nations people and perceptions of the patient-practitioner relationship. The literature suggests that a better understanding of both care patterns and patient-practitioner relationships will help form a better model of diabetes care, which could ultimately improve diabetes outcomes.

Chapter 3: Methodology

Design

The study was completed using in-depth ethnographic qualitative interviews and participant observation.

Population

The research took place in a small First Nations community on the Canadian prairies. The on-reserve population is approximately 620 people with 400 or so persons 18 years of age and older. Economic activities are limited. The band office, Health Centre, and local school provide employment. In the summer some people engage in commercial fishing, and a few build houses for the band. In the fall and winter, geese and deer hunting is popular. The community has its own school, band office, arena, baseball diamond, health centre, and church. The nearest town is approximately 15 km away, and has a hardware store, gas station, grocery store, hotel and restaurant. It too is relatively small, with a population of approximately 700.

The study community is nestled beside a lake and surrounded by farming country (mostly cattle farming). There are two main roads which intersect at the centre of town. This is where you'll find most of the community buildings. The roads are dirt with many potholes so most of the vehicles you see around town are vans and trucks. As in many First Nations communities housing is tight. However the houses are well spaced and well maintained. In the summer residents plant flowers and gardens and decorate their lawns.

Framework

A collaborative research framework guided the research. The Community Health Committee, a group of 5-6 people concerned about and dedicated to the health of the community, served as my steering committee. We have been equal partners in the research endeavour, synergizing my knowledge of research methods with their knowledge of community needs, concerns, and culture. The community first contacted my thesis advisor about possible research in the area. I took a trip to the community with a contact from the tribal council health authority and my advisor to meet with the Community Health Committee to discuss their concerns. I submitted a research proposal to the committee a few weeks later and returned to discuss and revise the proposal. Then the proposal was accepted by the committee and presented to the band Chief and Council who then consented to the research. The University of Manitoba Joint Faculty Research Ethics Board also approved the project. A letter was written to the provincial assembly of chiefs to inform them of the research.

Sample

Eligible candidates for the study included community residents (6 months and longer) who have had diabetes for at least one year, their family members, and those who provide care to people in the community with diabetes either as health care providers or administrators. All participants were 18 years or older and legally capable of providing informed consent.

Out of a total adult population of about 400, 42 people had been diagnosed with diabetes at the onset of the study. Six of those individuals are on dialysis, five of whom have moved out of the community for dialysis treatment. I had an opportunity to speak

with 9 people with diabetes – 6 women and 3 men. The Community Health Representative (CHR) recruited all of these participants. Attempts were made by the CHR to recruit both people who regularly came to the diabetes (“healthy living”) clinic and those who seldom or never came. A few individuals who were approached by the CHR refused to participate because although they wanted to support the study they did not want to talk about their sickness with anyone. I interviewed 7 people in a private room at the Health Centre and visited 2 people in their homes. During two of the interviews family members were present and their testimonies are included as key informants. The participants ranged from their early 30’s to their early 70’s. Duration of diabetes ranged from just over 1 year to about 30 years, although most people had had diabetes for 10-20 years.

I interviewed a total of 8 key informants. These individuals were family members of people with diabetes, health care providers, and health care administrators. These individuals lived both inside and outside of the community, but all worked directly with people with diabetes from the community and were familiar with the community. Key informants were interviewed usually in their homes or workplaces.

Before commencing the research I was asked to first take a few more trips to the community to get to know people. I attended a few healthy living clinics at the Health Centre and asked questions and got to know some of the regulars. Once I had become better known in the community, I put up signs recruiting for volunteers for the study. The signs said I wanted to interview people with diabetes about diabetes care or anyone in the community interested diabetes care. To aid recruitment I had a draw for a \$50 gift certificate for research participants. The posters were used to inform the community

about the study and to aid recruitment. Even with the signs, the CHR recruited all people with diabetes who participated in the study. The project steering committee advised me of whom I should try to recruit as key informants. I approached each of these individuals personally and most agreed to participate in the study. I did not inform the steering committee about which key informants I recruited to protect their anonymity.

Data Collection

Before each interview I explained the purpose of the project, the kinds of questions I had, and assured participants of their anonymity. I then reviewed the consent form (Appendix A) with the participant and obtained their written informed consent. The interviews were mostly tape-recorded, but when there were technical glitches and the tape recording device could not be used, I took extensive notes. See Appendix B for the interview schedule. After each trip to the community I wrote field notes on my reflections about the trip, how the interviews went and how the work was taking shape.

Participant observation supplemented the semi-structured interviews. I attended several healthy living clinics, spent time in the Health Centre, went to community meetings, and sat in the hospital waiting room, leafing through the few magazines that catered to aboriginal clients.

Ethics

The methods and procedures of this research project were designed to protect the interests of both participants and the community as a whole. The reader should keep in mind that ethical concerns are integral to the project approach. The ethics of research involving First Nations people is very important, not just to research institutions, but especially to First Nations communities themselves. The procedures and techniques that

were employed to maintain a high level of ethical responsibility will be clearly laid out in this section.

The ethics of research involving First Nations people is a concern for several reasons. Historically, researchers in First Nations communities (and anthropologists in particular) have had turbulent relations with First Nations people in Canada. Anthropologists have been accused of speaking for First Nations people and denying them a voice (Warry 1995). Some previous anthropological and health research on First Nations people has been founded on the assumptions that they were not able to analyse their own situations, or manage their own affairs. Today, First Nations people are insisting that all research in First Nations communities be conducted according to the highest ethical standards. They also insist that the research is salient to their communities and be focused on change. Many communities complain of being “researched to death”, while not seeming to benefit from any of the research projects.

Research conducted in First Nations communities today is inherently political (Warry 1995). The conclusions of the research – what is said about and for the community - is of import to First Nations. How the research is conducted is also of utmost concern to First Nations people. It is important to communities that they are not simply subjects, but participants and partners in research (SSHRC, NSERC and MRC 2000). As partners, they help direct how research is conducted, analyzed, and disseminated. This has been labelled “ownership” of the data. It is important that communities as well as researchers and research institutions benefit from research activities. Beyond achieving ownership of the data First Nations may also benefit from

the process of the research itself. Often this means developing local expertise (such as training research assistants or establishing committees).

As stated above, this research used a consensus-based decision-making approach. The steering group and I collaboratively developed the research approach, ensuring that the project reflected community priorities and approaches. The community has had input and ownership of the research during all phases of the project, which helped ensure that the interests of the community were given primacy. Through this partnership community members have had an opportunity to develop knowledge about qualitative research and issues regarding diabetes care in their community.

Research ethics concerns both the overall approach to the problem, and the protection of individual research participants. Upon meeting with each potential candidate, I first explained the purpose of the project and the kind of information being sought. I emphasized that their identities would not be revealed nor would any identifying information. I have been forced to alter certain facts to protect participants' identities. Participants were told they could refuse to answer any of the questions and could stop the interview at any time. If they agreed to participate I asked them to read and sign the consent form (Appendix A). All participants had high English literacy so translation was never an issue. An "oral consent received" checkbox was on the bottom of the consent form to be used if the participant was uncomfortable in signing his or her name. The participant kept one copy of the consent form which had contact numbers for myself, my thesis advisor, and the coordinator of the Joint Faculty Research Ethics Board. I kept another signed copy and stored it in a secure location along with all interview tapes, transcripts and field notes. The original data including the interview

tapes and quantitative surveys will be kept in a secure location for 3 years after the issuing of the final report. This data will be destroyed after the 3-year moratorium has been passed.

Data Analysis

The data were analyzed using thematic analysis techniques (Bernard 1988; Miles and Huberman 1994). I transcribed the interviews and coded the interview data and interview notes using the qualitative analysis software package Nvivo© 2.0. I went through each interview 3 or 4 times, coding and recoding. I then sorted through the different codes, merging, deleting and reorganizing them into tree structures. It was during this process of sorting through the codes and reorganizing them that I developed the structure and framework to present my results. Using Nvivo© 2.0, I was able to present the data in several different tabular and graphical forms to help me think through the data, make linkages, and “test hypotheses”.

Dissemination

I have presented the findings to the steering committee and received their feedback and comments, which have been incorporated into a final report, along with recommendations the steering committee and I developed together. This final report has been submitted to the steering committee and has been accepted. Once a final draft has been agreed upon, copies of the report will be given to steering group members, and the Health Centre, as well as any individual participants who request a copy. The steering committee will then send copies to the appropriate parties (e.g. the Regional Health Authority, the Chief and Council).

Chapter 4: Results

While reviewing the transcripts it seemed to me that people tended to talk about diabetes care in terms of three separate domains. First of all the **experience of living with diabetes**: diabetes self-care, the social impact of diabetes, and the difficulties of living with a chronic disease came out. These factors directly and indirectly influence how care is sought, managed, and understood. The people I spoke with did not neatly separate living with diabetes, having diabetes, and managing diabetes. They tried hard to show me how they could not separate these things because their lives, their struggles, and their disease were all interconnected. Diabetes is a condition that seems to be especially difficult on people because it requires constant management (or at the very least constant worry about management), and it has a day-to-day affect on social, physical, and emotional functioning. However, my informants with diabetes continue to face their challenges with determination and creativity. As one informant told me “I have diabetes, but I won’t let it have me”.

The second domain of diabetes care discussed was **formal diabetes care**. People with diabetes and key informants spoke about issues regarding obtaining, understanding, and negotiating formal diabetes care. Health care providers and administrators spoke at length about these topics. People with diabetes spoke about these topics but did not clearly distinguish between formal diabetes care and day-to-day care, as I have here. Thus, I discuss formal diabetes care separately from living with diabetes care mostly for sake of ease and understanding, but people with diabetes rarely spoke of the two separately.

The third domain of diabetes care that came out of the interviews concerns the **structural barriers to diabetes care**. Health care providers and administrators discussed these factors at length. People with diabetes were often very aware of many of these structural barriers but placed emphasis on those that affected their immediate circumstances. These structural barriers are yet another level of constraint that people with diabetes, health care providers, and administrators must negotiate. In the following chapter I will explore the relationships between living with diabetes, formal diabetes care, and structural barriers to diabetes care.

Part 1: Living with Diabetes

People spoke of a variety of different aspects of living with diabetes. These include self-care strategies for day-to-day management to avoid future complications, stress and emotions associated with living with diabetes, social factors they must consider regarding diabetes management, local knowledge about diabetes, how their disease affects all aspects of their life, and how diabetes is different for each person who has it. These general themes ran through the interviews with people with diabetes. Not everyone touched on each theme, nor did all people agree on what each theme – for example diabetes management – meant for them. I have tried to present the breadth of answers, while describing the central tendency.

Self Management – Finding Balance

All of the people with diabetes with whom I spoke talked about their struggles with managing their diabetes. They spoke about the particular things they do to manage their blood sugar, such as going for walks, getting exercise around the house, and reducing the number of high carbohydrate and high fat foods in their diets. People almost always then followed up with how hard it is to stick to the diabetic diet and get regular

exercise. For most people finding a balance between an ideal lifestyle regime and socially and financially viable lifestyle required constant juggling. The following quotes give examples of how people worked at finding balance.

Like, you're at a picnic and you see everybody eating these things and you can't. Me, what I do, but just like I eat half of what they eat.

It's difficult (to follow the diabetic diet). Especially when the wife cooks. You want to eat what she cooks, eh, what's on the table. But the most important thing is to drink lots of water. When I do that, that's when my sugars are on the low side.

I don't always cook all of those things (i.e. follow the diabetic diet) because my daughter stays with us, eh. They like eating, we'll eat it too. We will eat a little snack, eh. Crackers and cheese and stuff like that. I eat it.

Like I usually walk around and take my kids to the park. You know something that will like GET me moving. Like even if I'm home you know like, I'll kind of exercise but I don't like to exercise when my husband's at home. I don't like to exercise in front of him. (laughs)

Yeah, I'll admit too that I cheat once in a while. Like, you know, I will then go for a walk.

My informants with diabetes spoke of their struggles to fit an idealized diabetic lifestyle into their real world situation. They often mentioned family and social constraints to following a diabetic diet. For many eating a different or special diet was not only logistically tiresome but also socially undesirable. They either said they just ate less or tried to counteract the effects of the food on their blood sugar using other lifestyle interventions, such as drinking water or exercising. They often used the term "cheating" when referring to consuming foods not recommended for people with diabetes, implying feelings of guilt and self-blame. However, they often followed up with an assertion that they only "cheated" a little. My informants with diabetes seemed very aware of what foods and cooking methods they should be using, but they struggled with consistently

following the recommendations. It is not surprising that people found dietary management a constant struggle.

Trying to keep to the diet (is the hardest thing). But, it (the food others can eat without consequence) tastes so good. Then you get mad at that sickness. Why can't I eat it? It's draining.

But you have to control what you eat. It (sugar) comes with everything. Even I can't eat bread. When I eat bread, (my blood sugar is) sky high already. That's what I found out.

Because I'm scared to eat foods eh because foods today have so much sugar and you've got to really read the labels. It's like you're starving yourself. That's what I've noticed about being a diabetic.

Beyond keeping to the diabetic diet, people I spoke with talked about the difficulties of getting enough exercise. The barriers to exercise were often related to the consequences of having diabetes.

Well if you have the energy to do it (exercise) I think it's good. Well, I get sore feet eh. But I try to work as much as I can. That's what bothers me, my feet.

But I done a lot of walking. But I still walk a little bit. My legs ache (laughs). I'd walk oh, eight hours. But I'm getting weak in the legs now.

That's why I'm scared to kind of do sports now because the way my body feels sometimes like it's going to just snap.

People's experience with managing their medication tended to vary. Most people I spoke with were on oral hypoglycaemic medication. Two individuals managed their diabetes with diet and exercise, and one took insulin. One person who managed her diabetes through diet and exercise said that she has been able to control her blood sugar through diet and exercise since she lost a considerable amount of weight. Another who

was controlling his diabetes through diet and exercise simply hadn't been to the doctor because he was somewhat angry with the doctor and somewhat fearful of the disease.

Cause I just found out that I was a diabetic. I didn't... I told my doctor, the one I was seeing in the city before. He says oh, I can't... we'll just deal with your heart problem. We'll deal with that other thing later. And I say, well, that means that I have to come all the way back from where I'm living now to (large urban centre) to see you? And he says no, you go to (the nearest town with a hospital) and see the doctor there. And I says, what, what are you trying to do. I have to get my files sent out to there? And he wouldn't deal with this diabetic for me. And then I said, okay fine. If something happens, it's your fault. I'm just kinda scared. Cause I didn't see the doctor yet for it.

Those taking oral hypoglycaemic medication had varying experiences. This is not surprising considering the various types of oral hypoglycaemic drugs available and the various ways in which they work. When a physician does not have the results of an oral glucose test to understand the individual's blood sugar and insulin reaction to glucose intake, the physician often prescribes based on best guesses and past experience. Some individuals felt that their diabetes medication worked properly and they needed it to not only manage their blood glucose, but also their physical well-being.

If I forget it (diabetic medication) I make myself really sick.... Oh, you just don't wanna, you just don't wanna do anything at all. You just wanna be by yourself and lock yourself in. And I keep thinking I should have remembered my pills. But that feeling is so awful....

I don't find anything wrong with taking insulin as long as it helps. And I used to always be really tired and groggy and all that. Like, I don't know, before they started me on the insulin, like I used to um be really tired and grouchy and all that I guess with my sugars being high.

Others had more negative experiences with their medication. One woman found that her medication made her feel worse and worsened diabetes complications.

They gave me glyburide eh. Like after I had my son. And I found that every time I took it. It felt like I felt so like tired all of the time. It felt like my vision was going.... And today, today like you know I'm a diabetic and I stopped taking those pills and it's like my vision is coming back but I have to watch what I eat now.

For some people diabetes medication is an important part of day-to-day management. The medication not only helps them control their blood glucose levels but also helps them manage the emotional and physical side effects of high blood sugar. For others the medication disrupts their everyday functioning and is thus intolerable. Still others mentioned that they were on oral hypoglycaemic medication but did not elaborate on the medication perhaps because taking the drugs had become a normal practice of diabetes management.

Family Matters

The people with diabetes with whom I spoke all lived with family and were often visited by other family members. People spoke of how family matters impacted how they lived and managed their diabetes. Family dynamics impact diabetes management in very complex and unique ways. For many people concerns about their family influence them to control their diabetes. Thus they try to engage in self-care out of a sense of responsibility to their family, and with the understanding that caring for their loved ones means actively engaging in self-care.

Do I want to die from... clear myself of the diabetic? Put myself away on it? Or do I want to live with and suffer with it? So I said, Okay, I have a wife now. She doesn't want to be by herself and I don't want to suffer. I think oh, it's not the right way to do it. That sickness will get better.

Because, because like you know who's going to look after my kids if I happen to croak one of these days from diabetes because... I know that's why my dad died from.

Well, my previous pregnancies, my last two pregnancies my babies were kind of big and I didn't want the same thing to happen to this one. So I told my husband about that and he said why don't you just keep using the insulin. I don't want the baby to be too big he said. (laughs)

Where many of the people I spoke with seemed to be concerned about their health for the sake of their loved ones, it was also often the case that family issues impacted their diabetes management. For many people with diabetes the stresses of family life raised their blood sugar. This put them in a bind because they could not remove themselves from the immediate stressors in their lives (their family members) but tried to manage them as best they could.

You know, like I have a six year old that's really hyperactive. And I know it's like, you know when I get so frustrated like angry like sit still like come on you know. And I know my sugar's building up that way.

I was under a lot of stress too, like last month and in August I was under a lot of stress and stuff. My sugars were high and I talked to my kids about what they were doing to me and all that.

In addition particular family members were seen as either enabling their diabetes management or making it more difficult but not necessarily intentionally.

Sometimes I cook for them (her children) and I'll fry it and I have to boil mine or put it in the oven. And they'll always come to me and say mom why don't you have a piece of this. Just try it mom. Like you know. They want me to taste their food and I can't do that. Sometimes I just want to sit there and have what they're eating but I can't. It's hard.

Like when I check my sugars in the morning they'll sit there and watch me and they'll ask me how much my sugar is and that and like if I get a 10 point something reading they'll say (gasps) that's a little too high. Like they'll know because I tell them. They know it's too high and all that. And they ask me what I've been eating. My oldest one he's interested in that. He tried asking me like if he can give me my insulin. I said no way!

If they're passing out pamphlets about diabetes or whatever and sometimes I can't make it cause I have an appointment in Winnipeg. My auntie she tells me, or like she'll give me information sheets.

It (urine creatinine level) was going up and going high and they didn't want me to have complications later on. My husband was looking after me at the time. Why don't you go he said. He was always worried about me. Why don't you go and you'll feel better afterwards. I was scared eh. I was scared. He said there's nothing to be scared of he said.

The influence of family on the individual and the kinds of choices that individual is encouraged or able to make do not go unrecognized or unnoticed. One health care practitioner explained to me how family dynamics affect diabetes management and how and why the family can make it more difficult for the person with diabetes to manage their blood sugar levels.

The important thing with the family is not to think that that person is on a different diet or has to be treated in a special way, you know. If a person in the family has diabetes, chances are the other family members are going to get it too. If the lifestyle is causing it. So, I think that it is really important that the whole family become involved in change. I think that we're starting to get that message out. That it's not an individual thing. But often, I mean, with any person, even a person that goes on a diet, there's often people that sabotage it because they don't want to change and they know if one person changes in the family it might force changes they don't want to happen, or aren't ready for. You know, there's family dynamics there too.

However even if health care providers understand the link between diabetes management, health care decision-making, and family dynamics, they do not always have the resources to provide care on the family level. They are most often left caring for the individual with diabetes in isolation instead of in a family context.

Having family sessions and stuff is you know something, I think we could work towards but I think at this time we're still just trying to work with what we have (laughs) and that is often just being able to focus on the individual.

This clearly describes the conundrum health care providers have in addressing how larger social concerns impact people with diabetes and their ability to care for their disease. These larger social issues are often clear to health care providers but not something easily addressed by the health care system.

How Diabetes Affects All Aspects of Life

Living with diabetes means more than simply trying to control blood sugar levels. Diabetes is a very remarkable disease in that it affects such a breadth and range of systems – the kidneys, the eyes, the feet and legs, the heart and macrovascular system, the body's healing ability and normal flora. Because living with diabetes can mean living with subnormal functioning in a variety of bodily systems, living with diabetes, for some, feels like diabetes is constantly reminding you of its presence. It is something that peers around every corner.

And I said (the pills she takes for her diabetes) makes me so like tired, as though I'm not worth anything like you know, like the way my body feels like, like, yeah I'm alive but it feels like it's dead. Like the way it feels. Especially when my husband hugs me.

Um, you can't ignore it no. Because you know it's there. It's always going to be there. Like it's hard. But even like, say you scratch yourself and it doesn't heal right away and your scars end up going black or whatever. I don't like that. I've cut myself a couple of times and it was hard to heal and my scars would end up looking like dark from my diabetes.

But what really bugs me too is that yeast infection. Especially I get it, I get it easy. Especially when you've got your period coming and it will stay there during your cycle. And like, that's awful, like, you just want to scratch and oh, I can't (laughs).

Sometimes I don't sleep. I, I get worried. I get worried.

But for uh, for uh about a month already. Over a month now. It was August. For a long time already. You know I uh scratched them (her shins), I hit them on my wheelchair. I scratched them when I moved my wheelchair. Right here. Just a small little scratch and I don't know. It got so big. (Showed me her bandaged ulcers one on each shin. They

were quite large, the circumference of a small orange. I could see through the dressing that they were quite dark and there was a significant indent).

My informants with diabetes explained to me how various manifestations of diabetes – scratches that don't heal, yeast infections, problems with sleeping and lethargy – are the disease's way of reminding you that it's always there. The impact of diabetes on people's lives and general well-being ranged, but almost everyone I spoke with was concerned with how diabetes was affecting their quality of life. One of the most common negative impacts was the impact of diabetes on one's emotions.

Emotions

Most of the people with diabetes with whom I spoke talked at length about the emotional difficulties of having diabetes. I have already noted above that stress increases blood sugar levels, making glycaemic control difficult to manage for many people. However participants also talked about emotions such as sadness, worry, and depression that accompany having diabetes. Some people saw these emotions as a response to their illness whereas others saw them as yet another symptom of their illness. Some noted that diabetes is mainly a disease of the emotions. It affects your emotions and when you let your emotions get hold of you "the diabetes has you".

Emotional responses to diabetes came in many forms: worry, sadness, and anger, depression, and low energy. The following are examples of how informants' diabetes affected them emotionally:

Well, sometimes you don't know why you're yelling at someone and then you think why did I do that. (laughs) ... I don't know some people just came right out and told me that I was, that you're mean, they'd say. They'd say that. But I just, you know, you can't control it (laughs). You're really mean and you're not wanting to hurt them. It just happens, like, suddenly, a sudden bolt of anger (laughs). It just comes out.

And all of the time I'm angry and I take it out on her (his wife) or else I take it out on the kid.

Sometimes when my sugar gets bad, sometimes I just need a break eh. I'll just lock myself and try to cool off you know. Try and do a little bit of exercises here and there. Come back out. Sometimes I just have to go into my room and cry.

Like, I don't know, before they started me on the insulin, like I used to um be really tired and grouchy and all that I guess with my sugars being high.

And I start doing this (making crafts) and I like it. But sometimes when I think about uh, my sickness and then, then uh I quit everything. It comes to me eh. I'm happy and that thing will come to me and I just put everything away. It's pretty hard.

You know, some people don't know what it is. They should hear about what diabetes really is. I call it a depression disease. Because all it does is make you feel depressed. You don't feel any pain, just it's more like it attacks, your, your feelings. I don't know about other people, but I don't feel pain with diabetes. It's just the way it makes you feel inside. It's the depressed feeling.

Informants with diabetes talked at length about the anger, irritability, and depression that accompanied their sickness. Many felt that these emotional states were brought on by high blood sugar. People bring these emotions with them into their homes, their communities, and even to the hospital. People bring with them to the clinical encounter not just physical complaints and concerns and fears about diabetes complications but also anger, irritability, and depression. They told me that part of diabetes management was managing their emotional state – be it stress, depression, or anger. This was one of the biggest challenges for many, and one that had an immediate impact.

Diabetes Complications – a fearful present or an uncertain future

All of the people with diabetes with whom I spoke discussed diabetes complications. Some had already developed complications and described the worry, fear, and discomfort that these complications cause. Some who had not developed any

complications were taking specific measures to try to prevent complications, whereas others were not convinced that diabetes complications could be avoided. Finally others even saw diabetes complications as a direct result of biomedical intervention. However all of the informants believed that serious complications could develop from diabetes and were concerned about either managing these complications or developing them in the future.

Although all of the people with diabetes found complications concerning, not all believed that they could realistically do anything to prevent complications.

Interviewer: Do you think that if you're sick already, watching what you eat does much for you?

PWD: If only I had done it right from the start - try to control it, then maybe.... Well I guess if you're gonna be sick, you get sick. That's all there is to it.

This individual has had diabetes for over 20 years. He did not monitor his blood glucose when he was first diagnosed, and now he sees that any complications that might develop are out of his control. He had control over his diabetes when he was first diagnosed, but now after 20 years he sees that his control has diminished. Conversely, others were actively engaging in the prevention of complications. Individuals varied regarding which complications they were most concerned about, depending on their circumstances.

Like, things are really going downhill for her (someone she knows with diabetes) right now. She's on that dialysis. She'll bang herself, and she'll break her bones. She doesn't even know. She can't even feel it anymore. And I'm scared what if I happen to go like that? Like you know like the way her bones are going. That's why I'm always steady exercising, drinking milk and whatever.

(Physicians should) tell the truth up front. Tell me what you're, you're going to face later on. But I see a lot of people that have, uh, amputated limbs, so they can't get around.

They say that you can get blind by diabetes or you can lose a limb or something like that like if you don't watch your sugars and that. I've seen that on TV too. Like some people have like big sores on their feet for not taking care of themselves. I know that got me really thinking because what if I had a problem and they cut off a part of my body or something. That kind of scared me when I seen that program I thought I would try to do something about it. Like not trying to hide my diabetes. It just really got me thinking when I seen that. It's really gross (laughs).

I saw this person had diabetes. He just did his own thing and ate what he ate, what he had to eat. And this was diabetes for him. And he had diabetes. And then in the future he was getting sick. The next thing I knew he was blind. And then I got scared. So I took it seriously from then on eh.

For people with diabetes controlling blood sugar levels to avoid future complications is a difficult task. Although people were aware of the complications that can arise from diabetes because they have seen these things in their own lives (which is very different than being told about some abstract future condition from a health professional), making ongoing diet and exercise decisions based on an unsure future was complicated. It was complicated by the fact that short-term satisfaction and enjoyment is jeopardized for a possible future healthy state despite the fact that the individual felt fine.

So, I didn't even feel sick. I didn't feel you know. I was okay and the doctor said I had to go on dialysis.... Because I never thought I'd be like this. I never thought I'd be on dialysis to tell you the truth, I never thought I'd be this sick. You know. I was in good health.

I told her you don't feel sick when you have diabetes. Like that, you take it as a daily ritual. And I said that I've had diabetes for a while and I never feel sick until I guess my sugars go really high and I feel stress.

A review of the concerns people with diabetes have about complications would be incomplete without presenting people's views on how certain diabetes management practices actually caused diabetes complications. For many people diabetes

complications follow the initiation of more intensive diabetes treatment like insulin. Since more intensive diabetes treatment, like prescribing insulin to people with type 2 diabetes, is often undertaken when blood glucose levels are very high and have been high for a prolonged period of time, the people who do go on insulin have often already begun developing diabetes complications. But from a community standpoint “healthy” people who go on insulin or hypoglycaemic drugs develop serious complications. The following remarks capture this perception:

Cause so many times they have, they tried to put me on the needle, and I refuse it. The way I see it is that the ones that are getting amputated, that's the ones that are you know, shooting themselves with that insulin. That's why I'm sticking to the pills. Cause I'm on the maximum dosage of my pills. I think that was five years or ten years ago, that I was supposed to be on the insulin. The way I see it is that maybe you're giving your veins the insulin and that's why... and maybe you're killing them by accidentally hitting them, hitting the veins.

I'm supposed to take it (oral hypoglycaemic medication) but I don't want to take it. Because that's what I've noticed about native people ever since they started taking it like you know. I've noticed them yeah they'll start and when they get so much into that glyburide it seems like they go down hill. So that's why I come and you know kind of like scared too because my vision was kind of going eh and I don't like wearing glasses.

Because I told him, my dad was on that eh. His vision was blurry and then he was on that glyburide. Like he had to take two a day I think. And on top of that he ended up getting that laser surgery because of that glyburide. I, I blamed it on that glyburide. Cause my dad's vision used to be so good eh and ever since he started taking those pills his vision was going. His glasses were getting thicker.

One community member believed that glyburide was not an appropriate medication for aboriginal people with diabetes. In this case, there is a feeling that some medication is appropriate for aboriginal people and some is not. As a corollary, diabetes medication may be seen by some to be “white man's” medication and thus not appropriate for aboriginal people.

Part 2: Formal Diabetes Care

In this section I will present what people talked about regarding formal diabetes care. I have divided it into three sub-topics: seeking care, receiving care, and providing care. I have already reviewed the day-to-day difficulties people with diabetes experience regarding living with diabetes, including self-care. In this section I will present the findings regarding the barriers involved in seeking health care, the issues people with diabetes face while receiving care, and finally the issues facing people providing care. Most of the results presented so far have been from the perspective of people with diabetes. Again, much of this section is presented from the perspective of people with diabetes, but I also include the valuable perspectives and experiences of caregivers and health care administrators. I was not able to observe any patient-physician interaction so the results presented will be about their perceptions about those encounters and how they have internalized and made sense of them.

Seeking Care

For community members, seeking care is complicated by their rural location and economically limited choices. Thus people in this community face the same issues with obtaining health care as do people in rural areas and people with low socio-economic status combined. Most formal diabetes care is sought outside of the community. If people have concerns about blood sugar monitoring, monitoring equipment, prescriptions, and any other general questions or concerns regarding their diabetes they consult the nurse at the Health Centre. For any more serious or pressing concerns people must leave the community to consult a physician. If people do not have their own transportation, the medical van will pick them up from their homes and drive them to the

nearest hospital, about an hour's drive away. If people wish to seek health care from physicians elsewhere, they must pay for their own transportation unless they have a referral. Those with a referral receive gas money or a bus ticket. Thus the physicians at the nearest hospital are the only doctors available for those who cannot afford to seek primary physicians elsewhere.

Even though free transportation is available it is not always the best choice for people. When asked why these people choose to drive themselves to the hospital instead of using the medical van, I got the following responses:

Because there's always kids screaming and I can't stand it. Then I get worse by the time I get there.

No we drive ourselves. If you take the medical van you stay there all day. Our jobs require us to be here. We can't spend our whole day at the hospital when we work, for a medical appointment.

According to one key informant, First Nations community members are often expected to travel further distances and are allowed fewer health care choices than people in non-First Nations communities.

There are physical barriers, I mean, you have to look at what, what does that mean when a community health access isn't accessible and appropriate care. What is accessible? And it's not defined. And, my belief, what, what is deemed as accessible for a non-First Nations community is different than what's considered accessible and appropriate for First Nations. Well, I mean, there's lots of communities smaller than some (First Nations) communities that have physician services and small hospitals. You know? So, um, I think there's some, there are some issues there, that's for sure. Is it really accessible for people in (nearby First Nations community) to have to travel an hour and a half to see a physician? Is that accessible care?

People with diabetes generally were pleased when they received a referral from their general practitioner to see a specialist. They felt that the specialists were very

knowledgeable and trustworthy. However, travelling to the nearest large urban centre to see a specialist was often difficult for people.

For us it's hard to go out and see a doctor like that in (large urban centre) eh. We want to get travel (funding) from these people to go and see the doctor. (Field note: these people do not have a vehicle. They reported hitchhiking from the large urban centre to their community when they need to travel back and forth for non-medical related things).

That's why I prefer to go to the city, but like, you know, I just got married and you know it's kind of hard being a single parent with their step-dad. It's so hard. Just to get around. Like, to get a sitter or whatever, just to go to (large urban centre) just for an appointment. It's kind of hard to get a sitter.

Um yeah one (bus) comes here like six o'clock in the evening. Goes to the city. And when you want to come home, the only bus that leaves from the city is at ten o'clock and you get out here at one o'clock in the morning. That's really hectic. Yeah, especially when you have kids. You want to rush home to them right away.

One key informant understood the difficulty of obtaining care outside of the community as more than just an issue of logistics and economics. It was an issue of leaving the community and placing yourself in the care of system that is unfamiliar with and perhaps unsympathetic to the needs of First Nations people.

I think that's where the (diabetes) education off reserve doesn't work as well, the intimidation factor. I mean I know I would feel it if I was them going outside and you know, not maybe having that great of an education and feeling like people know more around you than you know, knowing that there maybe might be prejudice. Or.. there's lots of factors that I'm sure that cause them not to want to ask questions or understand things.

The remarks of some people with diabetes echoed this statement. The following are notes I made during a conversation with an individual who commonly sought treatment at the nearby hospital:

The atmosphere in the hospital is unwelcoming. There is a sense that white people get preferential treatment and aboriginals aren't wanted and their concerns do not warrant a

visit to the hospital. Some people don't want to seek health care at the nearby hospital because of the treatment and attitudes they have received. "You sit for hours even if you made an appointment". "After going to the hospital I felt terrible about myself because I wondered if I really should have taken my children to the hospital". She was made to feel like her needs were unimportant and she was wasting their time and she internalized the attack and questioned her ability to make good treatment and care-seeking decisions for her family.

The following is another excerpt from my field notes taken during an interview with an elder with diabetes and his wife who is very concerned about his health and accompanies him to all of his doctor's appointments and diabetes clinics. They explained to me what it was like for them to go to the hospital.

The hospital is very cold and becomes uncomfortable during long waits. Most waits are long at the hospital. Even with an appointment, they wait up to 4 hours to see the doctor. They believe that part of the reason they must wait so long is because the white people aren't made to wait and are can just go in and see the doctor. They feel that white people get preferential treatment.

Another woman with diabetes told me what it was like for her to go to the nearby hospital to receive treatment. This woman also spoke of how diabetes affects her emotions and she has a difficult time controlling her emotions.

It makes you feel, you're feeling OK in your heart and then you talk to the um, the secretary and she just..... Yeah, sometimes she is (in a good mood) and sometimes she isn't. And, just, you change so quickly from... your good mood just goes right off. Then you start, you just want to cry (laughs). And those feelings, they travel.

Many people with diabetes did not like to go to the nearest hospital, but could not afford to seek primary care elsewhere. Some of the people I spoke with could only afford to go to the nearby hospital, and are thus deprived of choice and autonomy. For these people, treatment at the nearest hospital is not considered a viable choice, but it is

the only one they are given. Two key informants brought up the issue of lack of health care choices for community members.

The tribal council health authority needs to be more sensitive to what's happening in (the town with the nearby hospital). They need to be flexible and allow people to seek treatment outside of (the town) and still be covered.

People should be given the opportunity for a second opinion. The informant doubted that an opinion from a second doctor in the same hospital was really a second opinion because the doctors most likely support each other's decisions.

Thus people were concerned about the lack of health care choices people in the community were given. Considering that people with diabetes should see their physicians regularly and that their physicians are asked to follow the rather rigorous diabetes care guidelines (Meltzer et al 1998), having a doctor that one confides in and trusts is rather important. In this community seeking care means two things – the struggles with obtaining (1) care at a distance and (2) care that is deemed appropriate and safe.

Receiving Care

Receiving diabetes care – whether it means attending a diabetes education clinic, going for a regular check-up with a primary care physician, or going to a specialist – was a complicated process for the study participants. Beyond obtaining the care they need, they must understand the advice or treatment, translate it into their own real-world contexts, and find the resources required to follow the treatment (or an adapted version of it). When talking to people about the diabetes care they receive, I asked them questions about the advice they were given, what kind of monitoring was being done and why, what they thought about the treatment they were receiving, and whether they could (or

would) follow the advice given. It is easy for this line of questioning to turn into “physician bashing”. I have noticed that almost everyone has a story or two about the incompetence or insensitivity of their (ex?) physician. Physicians are asked to understand and remedy our sickness and symptoms with kindness and compassion, precision, competence, and ease, but without haste or discomfort. Additionally, they must work on our bodies, which we ourselves know better than anyone, but do not have the medical knowledge to treat. That being said, patients do have a special perspective on the effectiveness and appropriateness of medical care. I have tried to present this perspective.

Since diabetes is a chronic condition involving several different bodily systems, many people with diabetes see a multitude of caregivers including primary care physicians, dieticians, and specialists. All of the people with diabetes with whom I spoke had gone to the nearest urban centre for diabetes care, usually to see a specialist for eyes, kidney or gestational diabetes several times. In addition everyone saw the doctors at the nearby hospital. Most had a regular physician at the nearby hospital but in the event of an emergency, or no appointment, they would see whoever was available. I spoke to people about the variety of care they received and their impressions of it. People varied in their responses. One couple talked about the different doctors and specialists they visited, both in the area and in the city. They were satisfied that the different health care professionals were well informed, as noted in the following passage from my field notes:

The different doctors they see at the nearby hospital and in the city fax each other information and keep each other up to date.

Another woman saw four different doctors in a large urban hospital for diabetes treatment. She did not think continuity of care was a problem for her. I asked her whether she sees them all regularly and she replied:

I'll see, well one will come there one week and uh, for a day or two and another will come the next day. You know they all like, they all know what's wrong with me, like they know exactly what's wrong with me and what to do with me.

Not all of the informants were comfortable with how their health care was divided between different doctors and specialists. Some responded to the bureaucratic nature of health provision with anger and frustration. One man talked about how a physician discovered that he had diabetes when he was being treated for his heart condition. The physician was a heart specialist and told him to see his regular doctor about his diabetes.

He says oh, I can't (treat you for diabetes)... we'll just deal with your heart problem. We'll deal with that other thing later. And I say, well, that means that I have to come all the way back from where I'm living now to (large urban centre) to see you? And he says no, you go to (the nearest town with a hospital) and see the doctor there. And I says, what, what are you trying to do. I have to get my files sent out to there? And he wouldn't deal with this diabetic for me. And then I said, okay fine. If something happens, it's your fault.

One woman complained of the lack of feedback from her health care providers.

PWD: Well, I go to these little clinics where the specialists are.

Interviewer: Um, do you see the same specialists?

PWD: No. Because sometimes it's for something else.

Interviewer: Is, is that uh, are you comfortable with that, with seeing different people all of the time?

PWD: Yeah, cause um, I don't know, I don't know why they send me there and then they never send me anything like the results of the tests.

Interviewer: So they send you to the city for tests and you never find out why?

PWD: Yeah! And then I ask, um at the health centre and then they'll look for it and sometimes you won't find it, like you'll just ...[indecipherable] and that's a waste of time for me.

Likewise, another woman showed her frustration with seeing multiple care providers.

When asked to describe the perfect doctor, she replied:

One doctor. One person that you could see all of the time.

From these responses, I would say that people generally do not object to seeing multiple care providers so long as they believe that they are being treated with care, proficiency, and by knowledgeable professionals.

That is not to say, however, that there are no issues associated with fragmentation of care. I found that when probing about exactly what kinds of things my informants saw different doctors for they often could not answer. They could not remember what doctor they saw for what or when they saw the doctor. This may be an indication that fragmentation of care is an issue for the community. Sometimes patients are expected to participate in their care – to be informed about diabetes care guidelines and pressure their physicians to adhere to the guidelines. As one key informant put it:

So, it's like a partnership. You're teaching and supporting the individual to manage their disease. But there's also things - it's like annual eye exams. You want the individual to have, you know, the self management such that I know I need an annual exam and I'm going to go make an appointment, but it's the ophthalmologist that needs to do that care, right? So, there, there, it's a partnership for sure.

Clearly, if people cannot remember whom they saw and why, they cannot be expected to cue their health care providers to administer timely secondary care treatment. This needs to be taken into consideration when looking at ways of “empowering” patients and encouraging them to take more responsibility in ensuring that their care providers follow the diabetes care guidelines.

Short physician visits are typical throughout Canada. Most hospitals and many private practices are structured on a fee-for-service basis where physicians are paid not by the hour but by the number of patients seen and the type of care provided to each patient. This encourages physicians to see as many people as possible in a day. Both people with diabetes and key informants discussed the problems associated with short physician visits. One of the problems is that people with diabetes who go to the doctor with a primary complaint are only treated for that primary complaint. No monitoring is done and the patient feels that he or she does not have enough time to discuss any other health concerns. Many people mentioned this problem:

Like, you sit there for the longest time and then by the time you get to see the doctor, you're always rushing. Then you're in and out. You never have time to say anything. ... Oh, you don't have time to ask, you know, to ask him questions. Because after you tell them what you're there for, that's it.

You just tell them what you're there for and that's what they check you up for when... I think the only time you get a check-up is when you go and ask for a physical check-up and you make an appointment for a physical check-up. But other times when you go and see a doctor you, you make an appointment to see him and you tell him what's wrong with you and that's the only thing they'll check you for.

Another concern with short physician time was lack of time to educate and inform the client about diabetes and the preferred course of treatment. Some key informants highlighted this outcome of short physician visits. They also suggested hiring nurse

practitioners to supplement physician visits and spend more time with clients educating them about diabetes.

And of course the physician time. You know, in and out, in and out. So, um, I'd prefer to see more nurse practitioners in our area, because the amount of quality of time and care is much better. That, um, that would be really beneficial to have more of those in the doctor's office so that when someone is diagnosed they could be, you know, maybe be given over to the nurse practitioner to go through things. Right there and then.

But I also know that in general, especially with fee for service physicians, volume of patients matters a lot more than quality of care per patient. Because after all, if you spend 20 minutes with a patient teaching them about diabetes, you could have seen 3 other people in that time. I know this for a fact because I worked in (name of city) in a fee for service system there too and this is the general feel I get. So, a physician has to be willing to sit down and take the time. If you're not going to be able to spend at least 20 minutes or a half hour for the first visit, you're not going to get the patient to even remotely start to understand what's going on with them, and I think that's a huge shortcoming, because we don't have that. I think if we could get nurse practitioners, or just nurses, just trained.

People with diabetes valued more physician time to give them an opportunity to direct the focus of care, to ask questions, and discuss options. Key informants valued more physician time to allow for patient education as a continuation and intensification of the practitioner's care focus.

Blaming the individual with diabetes for being unable to adhere to lifestyle management recommendations removes them from their social environments and gives the illusion that people can and should have complete control and autonomy over their bodies and lives. Likewise, blaming unsatisfactory care solely on physician's shoulders disregards systemic and cultural limitations of the clinical encounter. Doctors are constrained in terms of time and resources. They have also been socially conditioned to provide care in specific manners and relate with patients in certain ways. That being said, it is important to understand how health care constraints impact patients and how

they understand the work of physicians. Patients commented several times that physicians did not investigate their condition thoroughly. They complained that their physician did not do any tests or ask any questions. They interpreted their physician's neglect to investigate their concerns as a combination of a lack of proficiency, caring and/or time.

I call him a magic doctor. (laughs) Because sometimes he doesn't do anything. He just looks at you and then right away diagnoses what you have. (laughs). Funny.

Oh, there's one doctor I don't like at (the nearest town with a hospital). We call him the Tylenol doctor. He'll just look at you. He won't even give you a check-up and he'll prescribe pain pills for you.

I'll say one thing about him. When someone gets admitted in the hospital. I don't know if he ever makes his hospital rounds. He never comes around to see his patients.

To tell you the truth, that doctor out here, the one that I normally see, it seems like he just doesn't want to listen, you know. You know you try to tell him what's wrong with you and it seems like he's just guessing. That's what it seems like, like he's just guessing. Yeah.

We don't like to see the doctors at the (nearby) hospital. They don't look at you. The doctors there (except one in particular) don't ask questions or do many tests, they write prescriptions.

Those doctors aren't doing anything.

Whether physician treatment was interpreted as either a function of magical abilities or crafty guesswork, it was clear that many people did not trust their doctors. On many occasions people disagreed with their treatment regimen, whether it was a particular prescription, or course of treatment. However there were cases where people spoke highly of their care providers. In all but one of these cases the physicians they referred to were specialists with practices in the nearest urban centre. Interestingly, the only local

doctor of whom people spoke positively seemed to do the same things as the doctors people didn't like.

We used to have one good doctor. Dr. (name of doctor). You could go to see him anytime. Anytime in the evening eh. He'll see you, he'll just look at you and he'll be able to help. Sometimes you'll just see him on his doorstep and he'll write down something for the pharmacy to give you. Drugs.

In this case, prescribing drugs without doing a check-up was considered good practice. Perhaps the difference between this scenario and the ones above is that the doctor has made himself available and responsive to community needs by virtually being "on-call" 24 hours a day.

The comments made about specialists tended to focus on what the physician "did" in terms of running tests and asking questions. People regarded a physician's investigative abilities highly. In addition a few people spoke about their relationship with their physician. In these cases they had been seeing the specialists for a considerable length of time. For the most part people with diabetes valued a physician who ran tests, asked questions, and listened to them. They remarked that sometimes they did not understand the advice physicians gave, the medicine they prescribed, or a particular aspect of diabetes and how it works. This is not a feature common to only this community. However what was interesting was how community members internalized and made sense of this communication gap. Some responded with ever more persistence:

I ask them. What does that mean? I ask them. Because I have to know. And then they, they say this word you know. You have that. And you say what's that you know. Tell me, tell me about it. What is it? What does it mean? I have to know.... I'm very open. I can ask them if I don't understand what they're talking about. I can ask them. But sometimes they need to explain themselves what they're talking about. You know what I mean? No I don't know what you mean. Explain it to me.

Others did not persist in opening up lines of communication with their physicians after being unsuccessful a few times. They felt that their doctors did not care about communicating with them. This difference is affected by many different factors, including personalities, the duration of the relationship, the illness, and the perceived severity of diabetes.

One of the themes that many informants with and without diabetes discussed was that many people with diabetes faced racism in their encounters with the health care system. In particular, the poor service provided to First Nations people with diabetes at the nearby hospital was perceived as being at least in part due to race. Long waits, hostile treatment by hospital staff, accusations of not being “really sick” and abusing the system, and perceived lack of physician time and concern were all indicators of racism in the health care system according to many of my informants. Some concerns about racism have been presented above, but here I put all of these concerns together. The following quotes are from community members:

Even with an appointment, they wait up to 4 hours to see the doctor. They believe that part of the reason they must wait so long is because the white people aren't made to wait and are can just go in and see the doctor. They feel that white people get preferential treatment.

Some people don't want to seek health care at the nearby hospital because of the treatment and attitudes they have received.

After going to the hospital I felt terrible about myself because I wondered if I really should have taken my children to the hospital.

It makes you feel, you're feeling OK in your heart and then you talk to the um, the secretary and she just.... Yeah, sometimes she is (in a good mood) and sometimes she isn't. And, just, you change so quickly from... your good mood just goes right off. Then you start, you just want to cry (laughs). And those feelings, they travel.

Because of what appeared to be outright racism – giving Caucasian patients priority over First Nations patients and poor treatment of First Nations by hospital staff – the hospital atmosphere was interpreted as racist and unwelcoming and poor treatment at the hospital in general was felt to be racially motivated.

I spoke with a non-aboriginal physician who was very frank about the differential treatment aboriginal people can receive in the health care system.

I know from a fact from a lot of what they've told me is they're not treated as equals a lot. And it really grieves me. And I've seen it myself in some colleagues I've worked with, that there's a total difference between the way they'd treat an aboriginal patient and a white patient and I'm not talking... This happens among Canadian doctors everywhere. I've seen it and it disappoints me.

The physician also spoke of instances where other physicians have refused to treat their aboriginal patients because they believe that the patients were not actually sick, only claiming to be sick in order to get a free ride to town with the medical van. However not all key informants felt that community members faced outright racism while seeking health care. They felt that any inappropriate behaviour on the part of health care practitioners or hospital staff could be attributed to cultural ignorance and not racism per se.

I think a big problem might be that health care professionals don't know what the people on reserve encounter. Like more of an ignorance. You know, a person may be diagnosed um, and then they're sent home with the understanding that there's more care or more services for them, but really there isn't. So I think there's probably more ignorance on behalf of physicians about what is available in First Nations for them to access. Like, they probably don't know how little access they have to food. They might not realize that they have to travel an hour to the grocery store, and things like that. So I think probably it's more ignorance than anything.

I was unable to obtain any interviews with physicians or staff at the nearby hospital. It is unclear whether First Nations receive racially motivated differential treatment. However, it is clear that the hospital is considered to have a racist orientation toward First Nations people and therefore, community members with diabetes (as well as other community members seeking care) feel that they receive poor care because they are aboriginal.

Providing Care

I spoke with health providers and health administrators about the provision of diabetes care. These key informants discussed their experiences of providing diabetes care to the community; their thoughts, frustrations, and goals. They also discussed many of the barriers for the provision of care to First Nations communities in the area, but these will be addressed in the next section entitled “Structural Barriers”. The two liveliest topics centred on how to encourage people with diabetes to obtain treatment and how to encourage them to follow treatment. The results of these discussions are summarized below.

Several health resources are available to people with diabetes in the community. Physicians are available to help with diabetes monitoring and medication. In addition, the Health Centre runs a “Healthy Living Clinic” twice a month in the morning for people with diabetes and their families. First, people come in and have their fasting blood glucose level tested. Then the staff cooks a healthy breakfast (including eggs, toast, oatmeal, fruit, milk, juice, cheese and yoghurt) for attendees. Following breakfast, a presentation about a particular aspect of diabetes, diabetes management, or diabetes complications is given. Sometimes the dietician from the tribal council health authority

attends the healthy living clinic and gives a presentation or holds a question and answer session. At the healthy living clinic people bring up questions and concerns about diet, medication and possible complications. The nurse addresses their questions and often encourages them to speak to their doctor about their concerns regarding medication or possible complications. People with diabetes can also attend diabetes education workshops or get one-on-one diabetes education counselling at the nearby hospital. They must phone the diabetes education resource worker and book a time in advance. Key informants talked about the strategies they used to encourage people to use these services. They spoke about the importance of these services, but also how they may be improved, and interestingly, about how the simple use of these services would not necessarily mean better diabetes management, self-care, or outcomes.

Obtaining Treatment

The strategies key informants used to encourage people with diabetes to obtain treatment – whether diabetes education or a physician follow-up visit - were creative. Key informants spoke of the necessity of encouraging clients to obtain treatment. This encouragement was in the form of multiple phone calls reminding clients of their appointment, giving clients appointment cards, going to their houses to remind them of an appointment, providing transportation for any diabetes-related health care, and even visiting people in their homes to take their blood sugars and do basic diabetes counselling. Key informants tried very hard to encourage people with diabetes in the community to obtain diabetes treatment. Despite their hard work, they were not always successful, which sometimes manifested in frustration and ambivalence.

I try to refer all of them at least for diabetes education. Whether they show up or not is beyond our control. We usually try if they don't show up, to try one or two more times to

get them in, and if they've missed three or four times then you've got to give up because someone else could have taken that spot already. We do all that we can to encourage them, I think.

You know, so we found that we spent so much time trying to chase people who never wanted to come anyway. Or, you know, their phone number would be out of service or they would move, or, you know, it... it was very frustrating. We wasted a lot of time doing that. Um, so we've changed to a self-referral system and that seems to work better. You know, those who seem to really want the education, well they definitely contact us. And it seems to, you know, from our standpoint it makes our work more efficient.

I plead with them and say we want to help you but you also must help yourself.

Because we know that you can preach as much as you want but if a person isn't receptive there is no change that happens. Ultimately the person has to want to change or want to make changes that may help them or take their pills or whatever.

Following Recommended Treatment

Key informants also found counselling people to follow recommended treatment frustrating. These frustrations often sprang from their assumptions about how people should behave and that behaviour is primarily a rational decision.

Lots of people don't... you know, they just, say give me the pills and you know, I'll do the best I can with my diet and leave me alone, so... (laughs). It just depends upon the person.

I don't know how we can actually get them to that point, where they can actually learn yes you don't have to die, you don't have to go on dialysis, you don't have to have a heart attack. If you lose 20 or 30 pounds, you can throw your medicine away, you don't even have to take them anymore. Because I tell them that. You don't have to take pills if you can lose 20 or 30 pounds, you don't have to take your medicine anymore. But they just very few will actually start losing weight for you. Very very very few.

So whether they still do it (follow diabetes treatment) at home (laughs) is another question, but at least, I know that they've understood it.

I think a lot - not a lot of clients, but some clients. I think that they think that once they come to the classes, that's all they have to do. You know, they can go home and just do whatever they want. (laughs) But, coming to the classes and going to the doctor is their way of looking after themselves, you know?

And you know, there's some that just kind of sit back and don't really participate and you know, that's their choice and we don't pressure them to do that. It doesn't mean that necessarily they're not learning, but it's just their, their choice.

That people may “choose” to not follow guidelines that are strongly believed to improve their health and prolong their lives was difficult for most of the key informants to comprehend. They interpreted the absence of following health care provider suggestions, prescriptions, and instructions as a lack of education and awareness about diabetes. One popular suggestion from key informants was to intensify diabetes education in cases of non-compliance. The idea being that once people really understand how serious diabetes is and how to control it, they will more easily and willingly obtain and follow treatment, to the benefit of their long-term health.

It's about educating people. We can't expect a person who's never gone to medical school or who lives on a reserve who has a very sort of closed culture, we can't expect them to realize sugar of 18's bad. They don't even know that sugar should never be no more than let's say 6 fasting. Education again.

The people who come to clinic are mostly concerned with day-to-day diabetes management, but I want to educate them about long-term complications so they understand the importance of diabetes control to prevent the complications.

However the same people who suggested more education and better educational programs also discussed both how familiar people in the community were with diabetes and how difficult it must be for people to motivate themselves to manage their diabetes when they have only seen poor diabetes outcomes in their communities. Again, health care providers face the burden of having to “convince” people that the only reality that they have experienced in terms of diabetes outcomes is not the only possible reality. Clients' inability to be convinced of this alternate reality is interpreted as fear or denial.

A lot of them, especially another lady I have now, doesn't seem to be interested in doing anything because all her family members had diabetes, all of them died from complications, so she figures I'm going to die anyway, I have diabetes. And I have the hardest time to tell her it's completely within your control whether you're going to die from diabetes or end up on dialysis, whereas most of her family members either died from heart attacks or from gangrene or went on dialysis and eventually passed away from that. But a lot of patients I see, diabetes is nothing new to them. They've been living with it for years within the family and they just figure well, I've got diabetes, I'm probably going to die from it, so... For them to grasp the concept that they can actually control your future by adhering to the regime, it's hard for me to get them to go for that.

Because I think, um, a big part of it is fear. You know, I think that they're afraid of having diabetes. Um, often they'll see a parent or family member really sick with it or on dialysis. There's definitely a fear. And denial.

Oh I do think they see it as serious, yes. I think they'd rather just not know if they have it. If they do have it they'd rather not know how bad it is because they know mom died of it and they think I'd rather just not deal with it. It's more of a denial thing than anything else that I have experienced. I don't think it's laziness or ignorance, I think it's a concept of denial; they don't want to have diabetes. My parents died from it, I'll just pretend I don't have it, but I know I have it and I'm going to die anyway.

I asked people with diabetes and key informants what part of diabetes care they thought was the health provider's responsibility and what part was the client's responsibility. All informants agreed that the person with diabetes has more responsibility and control than the health care provider. Key informants felt that the clients had ultimate control over lifestyle change and treatment adherence. The care provider's role was one of education, support, and encouragement.

Blood sugar control is primarily the client's responsibility. Health care providers give information.

You know, knocking on people's doors over and over again if they don't want to see you isn't going to do anything. Um, but having that service available and, and you know working at making relationships like I said earlier, that has to be the responsibility of the health care worker.

I think education is definitely, explaining to patients, what is diabetes, what are the consequences, what can you do about it, you know. And encouraging patients not to lose hope or belief that they're going to go to an early demise because of the disease. It's very important because people think oh God I've got diabetes. Doom. You know? Walking around with this kind of doom around their heads for the rest of their lives is not good. Apart from that, we have to make sure the patient (know the contacts in the community). The patients don't know the contacts in the community that can help them.

However the key informants who worked in a clinical role also discussed physicians' responsibility to follow the diabetes care guidelines. For these people, careful monitoring of the disease progression was of high importance but also something that seemed to be lacking for people with diabetes in the community.

I am very disappointed in the quality of care that diabetics receive in this community. That's my first statement that I really feel strongly about.

It's not that the doctors aren't educated. Doctors are over educated about this stuff. It's whether they're going to apply it in practice or not is the problem. To me that's always been the problem.

No one told me why he or she thought physicians in the area are not following the diabetes care guidelines. However, poor adherence to diabetes care guidelines is common among physicians (Martin, Selby and Zhang 1995).

“Compliance”

The final perspective from key informants I would like to review is on the topic of patient compliance. I did not ask specifically about compliance, but I did ask questions like “Why do you think some people are able to control their blood sugars while others aren't?”. This was interpreted as a question about why some people comply with diabetes treatment recommendations while others do not. According to the biomedical model, specific exercises like monitoring blood glucose levels, taking oral

hypoglycaemic drugs as prescribed, counting carbohydrate consumption, and 20 to 30 minutes of walking each day are considered mandatory for managing blood glucose levels. From a biomedical perspective poor blood glucose control is often a sign that these treatment recommendations are not being followed. Therefore a discussion about “blood glucose control” often moved into a discussion about “compliance”. Key informants’ reasoning about why some people with diabetes could or would not comply with their diabetes treatment regime included ideas about **Aboriginal culture**.

A lot of people don't believe in medicine. I see a lot of my patients will say I'll go to the traditional doctor and see what they can do for me. I don't like to take pills. That's another one that I'm having a difficult time with, because a lot of these people don't want to take pills.

However, some people also spoke of **social factors** that would enable or inhibit someone to comply with diabetes recommendations.

Um, social concerns are in fact the major part of it. If you have any support at home, or you know, are having troubles with abuse, or you know any kind of social problems or emotional problems, depression, you know, your ability to manage things.

Interestingly, when I asked people with diabetes whether they thought more education would help them manage their diabetes more effectively many said yes but went on to describe how it would help others in the community and not themselves. They too had an image that others in the community needed more education.

And I think maybe something like you know, like, somebody needs to teach them how, how to do it around here. Like for diabetes. All the exercise. All of the eating. Cause I usually see a lot of them cheating lots. Eating fat. And so on and so on and they're always complaining about their diabetes. Like oh you know, my sugar's up, my sugar's up. And you see what they're eating. They're eating all of this fast food. Whatever. Fatty foods and everything. And they're always asking me how do you control it? I said

you know, I'll be honest, yeah I cheat once in a while, yeah. But I don't overdo it when I cheat.

It is possible that other community members with diabetes eat fatty foods because they do not know that these are not recommended foods for people with diabetes. What is more likely is that they have a hard time *not* eating them and asked the above participant for advice on how to stay away from them. Another informant with diabetes commented on the lifestyle choices of other people in the community with diabetes.

What I think is that people should have to try to change their eating habits. That's what I was like. I had poor eating habits. Like always wanting junk food and that and then when I realized what I was doing to myself and saying to myself, like why would I put my health at risk, being a diabetic and trying to be a junk food eater all the time (laughs). I thought I would change my lifestyle and I did (laughs).

I found that both health care professionals and people with diabetes shared the assumption that many who cannot follow lifestyle choice recommendations are "uneducated". This reinforces the compliance approach to diabetes care and management, increasing self-responsibility and empowerment but also self-blame and hopelessness.

Part 3: Structural Problems

Key informants spent a great deal of time explaining to me the various structural issues which, if fixed, would improve diabetes care for community members. People with diabetes did not discuss these structural issues specifically because as patients they are not always aware of them. However they did discuss the ramifications of many of the inefficiencies brought on by these structural issues, such as frustration regarding obtaining medical information and receiving diabetes education.

Jurisdictional Issues

People with diabetes from the study community obtain diabetes care in different locations and from different specialties. There appears to be a strong divide between on-reserve and off-reserve health provision, impeding communication. The on-reserve health care is provided by and paid for by the band. Ultimately federal dollars fund these programs. All off-reserve health care is provincial health care. This health care is only available off-reserve and is not tailored to First Nations people even in areas such as the one in question where there are numerous First Nations communities all with high rates of diabetes. An aboriginal advocacy program exists in the region, where an advocate can work on behalf of an aboriginal person being treated in one of the provincial hospitals. The duties of the program include arranging for an interpreter if required, bridging patient-practitioner communication barriers, and informing the physician of the client's home environment (availability of running water, homecare, particular foods) to help ensure they are not discharged early. The people at the Health Centre were aware of this program but did not consider it a resource as only one advocate is available for the entire region and has never contacted the community. They believe that the program is of no practical value to their community.

Provincial health care does not extend to First Nations communities. Provincial health care is available to First Nations people but never in their own communities, regardless of the size the community. As one key informant explained the jurisdictional boundary between the province and First Nations communities (which is considered federal) is a matter of practice, not legislation, and is it not consistent throughout the country:

Well, they're stated as jurisdictional issues, but that's a false statement. There's nowhere, nowhere, does the (provincial government) say thou shall not set foot on reserve. I mean jurisdictional issues, yes they're treaty based, but they're basically a decision by the government. I mean, it's not written in the legislation that (the province) cannot provide services on reserve. It's just more of a practice. Home care is a perfect example. There was an order of council from the government in the 70's that you can't even find in the archives. They just decided that it wasn't their responsibility. So, you know, we're one of a few provinces across the country that's done that but others willingly provide homecare on reserve. So, there's not a national standard there. It isn't something that is stated. It's just a matter of practice.

This jurisdictional issue means that people living in First Nations communities have decreased access to programs like Baby First (a home visiting program for babies at risk), homecare, and diabetes education services despite the fact that First Nations communities have the lowest health status in the province. Thus for First Nations people to access these programs they must either go out of their communities (where appropriate) or the bands and tribal councils themselves must find sourcing and develop their own programs.

The imaginary health care line that runs along the borders of First Nations communities does two things. First, it inhibits access to diabetes education programs, which many key informants believe to be a key to improving diabetes outcomes. Second, it blocks the communication between on-reserve and off-reserve health care providers, causing confusion and frustration for both health care providers and patients and inhibiting continuity of care. Many key informants spoke about how they had been struggling to get the provincial diabetes education team to come on reserve. As they saw it this would increase the number of people receiving diabetes education and perhaps its effectiveness. They believed that moving the educational sessions to on-reserve would increase the comfort level for clients. In addition it might encourage collaboration between the community and the diabetes education team to create workshops targeted to

First Nations. From the perspectives of those working in or with the study community it was a question of access to resources and fairness.

And then you know, with the provincial health – FNIHB (First Nations and Inuit Health Branch) relationship and how there's like these jurisdictional boundaries that always come up and umm, the relationship is always so strained between the two. That also is difficult because there is diabetes care from the province, but it doesn't necessarily filter down into the communities. Outside the (First Nations) communities, they have public health and they have a diabetes resource team. Inside the communities they basically just have the public health nurse and she's expected to do the whole thing.

There's always been that "we don't go on reserve" because that's federal and we're provincial, but yet community members are invited to go to their diabetes clinics off reserve. Which in itself, I mean, you know, people say why don't they, but there's always that hesitancy, of you know, First Nations going into a white group, and so it would be very nice if they could come on reserve. I mean that's where the majority of their clients are.

The diabetes education team not coming on to reserve. It's huge. It's a huge issue in terms of appropriate care, acceptable care. Care, care that's an hour and a half away in a group setting that may or may not be familiar or comfortable to an individual is not appropriate care. Those, those are tenets of our community health care system.

A member of the diabetes education team spoke about the difficulties of arranging for the team to visit reserves even though the diabetes education workers were in favour of the change.

Yeah, we've been, actually we sort of initiated um, communication with, with the tribal council health authority and also with (name of study community). Um, just to, because, you know, for the reason being that we want to improve diabetes education for the aboriginal clients in our area. We're not, you know, we're not seeing enough of them. So, we, you know, we had meetings with them and so on, but we were very frustrated by the political part of it and the jurisdictional boundaries and, I think they are addressing that at the higher levels, but we don't really have any control over those things. Um, so, that's a big frustration too. You know, we want to include them. And we are you know, we are doing the best that we can.

When asked why diabetes education wasn't being made available on reserve if all sides agreed on it and there were no actual judicial obstacles, people cited lack of resources, hesitancy to extend services, bureaucracy, and fear of job loss.

(The reason the province will not agree to go on reserve is) partly maybe resource, but um, I also think there's a reluctance to start into that type of care arrangement, because they probably don't know where that's going to lead. They start extending services on to reserves, the province probably wonders well what else then.

Okay, so they said that there's no travel budget to go on reserve because it would be a lot of extra travel for us. We're only part time, right?

From my field notes: She felt that since the initiative is "streamlining" and "amalgamating" people don't want to discuss it much because it they are afraid that it will mean their jobs.

These jurisdictional issues are clearly a source of tension and dispute. They reinforce the division between aboriginal people and the general population. It is interesting that the government is perceived as being hesitant about giving more resources to First Nations communities because "what else then". However, jurisdictional issues also functions as barriers to maintaining consistent care in on- and off-reserve populations.

Many key informants described the lack of communication between health care providers on- and off-reserve, specifically between physicians and the community Health Centre. Absence of communication prevents health care providers at the Health Centre from following up with people with diabetes, either at the time of diagnosis, or in the event of a change in prescription or health status. Many suggested instituting a system where the nurse at the Health Centre would be notified of new diabetes diagnoses in the

community. This would allow the nurse to follow up with clients and provide them with resources and education.

But if the person doesn't quite understand what they have or how important it is, even if that physician is saying, you know, go get educated on this. Not having somebody else... contact that patient, um, is a barrier. So, only having that one person contact and diagnose and then not having any other health team member know for a follow-up is a huge gap. So, we've been trying to say, you know, anytime a person is diagnosed they should contact our community. But, they haven't been successful.

One of the issues we have right now is, um, physicians aren't referring people who are recently diagnosed with diabetes to the health nurse. They're giving individuals a referral form. Someone may say that people have to take responsibility for their disease. But there's also a historical way of health provision in the community. Most people will go through their community health nurse in terms of arranging their care, and sort of looking out for them. And that initial referral allows the nurse to go and say, I hear you're newly diagnosed, come to the diabetes clinic. Work with people around that whole mental health piece, around being diagnosed with an illness, and then invite them into the clinic and work with them in their community setting. If that referral never happens, you know, that right there is a huge barrier. And it's not a partnership between the doctor and the client, but a partnership between the doctor and the nurses in the community. And that's in the best interests of the client.

In my field notes one key informant suggested: *Communicate with the staff at the nursing centre. Inform them of newly diagnosed diabetics. They are a resource and can help educate, inform, and support the newly diagnosed. Physicians inform each other of treatment, but the nursing station is never informed. There seems to be a different standard of communication for the nursing station.*

When asked about whether physicians could (ethically, logistically) communicate with the Health Centre and would be interested in doing so, one physician replied:

I'd be most willing to talk to them.... I certainly don't think the doctors would have a problem.... It's not a big deal. It's no big medical legal issue that I don't think hang over you.... There's nothing threatening about that. I don't know why it's not happening.... I'm sure it (informing the health centre about newly diagnosed people with diabetes) would be ethical if the patient gives us informed consent. We have consent forms that we have in the clinic that we made up ourselves that you can sign. I think most clinics have them where you can sign a release of information. So that's not a problem. Not a problem at all. What I would do if that were the case, I would just fax my notes and recommendations that I just made and just use my notes, but I've never ever done that.

Never. Never even came up in my head that I could do that actually. I wouldn't know who to fax, what number, you know, who to even start asking. There's absolutely no communication. That would help a lot. You know, that would help a lot.

The Personal Health Information Act prohibits health care practitioners from volunteering health information about clients to people not directly involved in the client's care. In order for a practitioner to share information to third parties, the practitioner must obtain written consent from the client.

The physician also added that increased communication between physicians and on reserve health centres would improve access to health care:

I for one would definitely use that opportunity because a lot of people don't have vehicles; they have to wait for the medical van to get out. A lot of times the medical van is booked and they can't get out. You know it's very difficult for people to commute sometimes, as well, so they're kind of stuck a lot of times. It's not right. You know, we're not doing much to help them in that area, in accessing treatment.

Currently some people with diabetes are frustrated by the lack of information the Health Centre has about their medication and their test results. As a person with diabetes stated:

And then I ask at the health center (about the results of tests done in the city) and then they'll look for it and sometimes they won't find it, and that's a waste of time for me.

Community members look to the Health Centre for information and help and when the Health Centre cannot help them because they have no communication with the physicians at the hospital, their perception of the proficiency of the Health Centre diminishes. Increasing communication between physicians and the Health Centre would of course

increase the Health Centre's knowledge of patient's needs, enhancing its reputation within the community:

Clients are more likely to see us as a resource if the communication is there.

A final structural barrier is access to healthy food and exercise opportunities. There is no store in the study community. The nearest store is 15 km away. It is a modest grocery store which services a few small communities in the area. Most people do their day-to-day shopping here but stock up on larger quantities of foods when visiting larger centres. Fruits and vegetables are available locally although the quality is variable and the selection is sometimes lacking. That being said, the community has access to cheaper and a wider variety of foods than many First Nations communities, especially those in the far north. However people with diabetes often complained of not having the funds for "special diabetes" foods. These included cans of enriched milk, sugar-free desserts and snacks, and "stuff in bags" – health foods that were used during a diabetes cooking instruction class one of the participants attended in a nearby town. Not only were the foods they used cost prohibitive but so was full participation in the class. This is what she had to say about the class:

PWD: I went to one place in (name of town). I don't know what it's called. I guess they show you how to eat eh and what to cook. She showed me so many things there. What I can eat eh. But they're expensive those food.

Interviewer: What kinds of food do they recommend?

PWD: Health food.

Interviewer: So, I don't, I don't really know what health food is (laughs). Can you tell me?

PWD: All kinds of stuff in bags.

Interviews: Special grains? (participant nods her head yes). Oh okay. Right those things you should eat but they're not affordable.

PWD: I just went to check it out. They cook for you there.

Interviewer: Was it good?

PWD: I didn't get to eat. You have to pay to enter that.

This individual sought out this diabetes cooking instruction class, arranged for transportation, and attended the class. Clearly she was interested in learning more about how to prepare foods appropriate for diabetic diets. However the class was not useful to her because she was not able to apply the teachings in her own kitchen, nor was she able to see for herself whether the foods were satisfying. Likewise physicians and diabetes educators may assume that people on reserve have access to exercise facilities. There is a baseball diamond in the community and the school has a gym, but it is reserved mostly for students. In the summer the roads are dusty in the spring and fall and muddy in the winter difficult to walk on. Wild dogs are always a safety concern, discouraging people to go for walks, especially alone.

Chapter 5: Discussion

Part 1: Explanatory Models – Patient and Practitioner Variation

For community members with diabetes can the current dissatisfaction regarding care be related to the difference between explanatory models of patients and practitioners? Moreover through understanding these differences, can care be improved? As is the case between patients and practitioners whoever they may be these two groups have very different explanatory models. Can this difference help communities understand dissatisfaction regarding care and take steps to improve diabetes care? I believe that the explanatory models theory can give us some insight into care provision, interpretation, and implementation. Using this model we can understand care in terms of how it is impacted by the clinical encounter. Certainly the clinical encounter – the interactional space where the sick and the healer meet, negotiate, and understand disease – has an impact on care. However as I will subsequently explain, the clinical encounter is tied to a larger institution of care. This institution enables and encourages certain types of care. In addition for most people with diabetes the majority of interactions with the health care system are done outside of the clinical encounter where other personalities and authorities are engaged.

I will first review the differences and similarities between patient and practitioner explanatory models, especially with respect to diabetes care. Then I will discuss how these differences might affect both self-care and delivered care. Finally, I will relate this to the literature on diabetes care and explanatory models, highlighting where an explanatory models framework falls short.

Treatment

1) Pragmatism

It has been recognized that the primary differences between patient and practitioner explanatory models of diabetes is that practitioners' models are based on reasoned diabetes management, abstracted ideal practices based on how certain activities and treatment regimes impact diabetes pathology. In contrast patients approach diabetes from a very pragmatic perspective and strive to manage the demands of diabetes treatment within the constraints of their own lives (Hunt, Arar and Larne 1998). Patients often "fall short" of what their caregivers wish them to achieve in terms of glycaemic control and lifestyle modification. This can create some anxiety for the patient (Ferzacca 2000). The people I spoke with were indeed pragmatic about managing their diabetes. However I believe that they were pragmatic not in the sense that they were satisfied with doing their best in light of the constraints they faced. They were pragmatic but often spoke about their frustrations and dissatisfaction in how their diabetes was controlled. This "dissatisfied pragmatism" was clear in two areas of diabetes care: medication and diet. Interestingly, practitioners too were very pragmatic regarding the diabetes care they could deliver. They tried to "do their best" but were constrained in terms of time and money. Thus in terms of treatment EM's both patient and practitioner share similar stories about lack of resources and doing the best they can with what they have. Of course they are working in different arenas but share similar frustrations and outlooks.

2) Diet and Exercise

Patients and practitioners agreed that people with diabetes ought to control their diet as much as possible, to cut down on alcohol, and get regular exercise. Many people

with diabetes spoke about how their diet and exercise patterns directly impacted their blood sugars. In addition both people and practitioners understood how difficult it is to lose weight and to follow the recommended diet. Practitioners were sympathetic to how difficult it is for many people with diabetes to lose weight. However practitioners in general felt that if people could not lose weight they required more education about diet and exercise. People with diabetes also felt this was the case – for other people with diabetes. Few people told me they felt they needed more education about diet and exercise. Their problem is that they were having a hard time implementing change. This may be a reflection of the population I interviewed. Most people had had diabetes for at least 10 years and in general had a good knowledge of diabetes.

3) Medication

Most people with diabetes are prescribed medication to control their blood sugar and/or blood pressure. All of the people with diabetes with whom I spoke had been advised by their physicians to take medication or insulin to manage their blood sugar and/or diabetes complications. Not all of these people actually took their medication. Some had their prescriptions filled but didn't renew them or take the medication. Others who did not take their medication were more open with their physicians, flatly refusing to take it. To physicians medication was a safe and effective way of managing diabetes. They had faith in pharmaceutical treatment. People with diabetes did not have the same faith in the medication. Many people distrusted oral hypoglycaemic drugs, insulin and/or other medication for controlling complications. This is different than Hunt, Pugh, and Valenzuela's (1998) findings in a Mexican-American population. People with diabetes in that population tended to rely on medication to help them manage their blood sugar when

they were unable to follow the lifestyle recommendations. They trusted the medication and used it as a tool for day-to-day management. I found many people suspicious of medication. Some did not think that certain drugs were appropriate for First Nations people. They had a sense that the drugs physicians prescribed weren't in themselves dangerous but were so only when used by First Nations people. This may be somewhat related to the notion that diabetes is a "white man's" disease (Garro 1990). Other informants observed that people who go on insulin develop serious complications, linking insulin with diabetes complications. Abonyi (2001) also found this perception in the Cree community she studied.

The idea that certain drugs might be dangerous to certain ethnic groups is not common among practitioners. However some practitioners did discuss how their "native" patients did not like to take drugs. They attributed this to a desire for more traditional medicine. However community members' distrust developed from knowledge and observation of bad experiences and outcomes using the drugs. These experiences made them question the nature of the drugs. Practitioners' assumptions about patient's attitudes about medication preclude them from addressing the real issues their patients have with the medication. It would be advisable for physicians to take the time to understand whether their patients are apprehensive about taking certain medications, and how the medications make them feel. In this case, as Arthur Kleinman suggests, if physicians elicit patient explanatory models of diabetes pharmacological treatment, they would be able to address and perhaps "negotiate" the different explanatory models. It is not to say that eliciting explanatory models should be a method of increasing drug compliance. Simply put, understanding whether a patient will begin to take or continue

to take prescribed medication is important to understand whether a particular care trajectory is viable. If it is not then the patient and physician must discuss what other options are available. It is not about compliance but rather about finding a method of care that will be implemented satisfactorily. It is also about developing a relationship where patients do not feel that they should make their physician “happy” by agreeing to take their medication whether they intend to or not.

Course of Illness

1) Emotions

For the people with diabetes with whom I spoke, managing the emotional complications of diabetes was often the most difficult part of having diabetes. Wang and colleagues (1999) found similar responses from the native Hawaiians with diabetes with whom they spoke. People with diabetes in the study community experienced many emotional complications of diabetes – depression, low energy, sadness, and fear. When the participants felt depressed or worried about the future, they talked about a sense of hopelessness and inability to manage their diabetes. Ironically, these same people showed determination and creativity in managing their diabetes. They were very concerned about their health. Although they admitted to feeling hopeless at times they showed resilience and courage. They discussed how diabetes impacts their relationships with their friends and family members, in addition to their energy levels, sleep patterns, and self-esteem. All of these complications have an impact on how they view diabetes as a disease. For many, diabetes is not about controlling blood sugar. It is about controlling and understanding ones moods and emotions. It is a condition that is best dealt with by “not thinking about it”, or by “not letting it have control over you”. Franciosi and

associates (2002) found that excessive time spent “controlling” diabetes proved very negative for many people with diabetes. They found that for people with type 2 diabetes daily blood sugar monitoring did not improve glycaemic control, but it did increase feelings of anxiety and stress. Therefore they made the recommendation that people with type 2 diabetes not engage in daily blood sugar monitoring. This is a bold statement because blood sugar monitoring is considered one of the best tools people with diabetes have for managing their blood sugar and their disease outcomes.

The practitioners I spoke with mentioned how stress levels can increase blood sugars. However, they did not give this much consideration and did not consider stress management a considerable part of blood sugar management. In addition, they did not fully appreciate the mood swings, depression, drop in energy levels, and loss of self worth that many people with diabetes experience. However, they did recognize that people with diabetes tend to express certain emotions such as denial and hopelessness. They felt that fear, denial, and hopelessness were socially inappropriate ways of dealing with the diabetes and did not contribute to improved health outcomes. The assumption here is that disease can be overcome if openly addressed, understood, and treated with vigour and courage. This heroic narrative may not be culturally salient to First Nations people who have struggled and fought for political and resource rights, and yet have not “overcome”. In addition, this narrative requires a positive orientation to disease management, which may be very difficult to achieve while suffering from the emotional and depressive symptoms of diabetes.

As we can see, patients and practitioners have very different understandings of the role of emotions in diabetes. Patients see that emotional upsets and difficulties are part of

the disease. In fact they are often the most difficult dimensions of diabetes to manage. In contrast practitioners see the emotional responses to diabetes as individualistic and voluntary, not an element of the disease itself. This difference in explanatory models acts as a barrier for practitioners in addressing their patients' concerns about the emotional impacts of the disease. Moreover, the relationship between the patient and practitioner is strained because the patient is seen as someone inappropriately responding to disease and the practitioner is seen as unsympathetic and one who does not listen.

2) Stress and Diabetes

The difference between the role of stress as understood by patients and practitioners has been discussed above. The role of stress in diabetes was discussed more by patients than practitioners. This is very interesting in light of recent research on the relationship between stress and diabetes. Much has been said about why diabetes is pooling in indigenous populations across the globe. What is being said and who is saying it is of interest because "population health, its study and surveillance, and interventions guided by health information are thoroughly and inescapably political" (Rock 2003:164). Obesity, and in particular central obesity has been associated with diabetes (Evers et al 1989, Young and Sevenhuysen 1990, Harris et al 1997). The fact that there appears to be a link between obesity and diabetes has focused research and diabetes care on understanding and changing patients' lifestyle choices. However there also appears to be a link between diabetes, central obesity, and stress (Mooy et al 2000; Bjorntorp, Holm, and Rosmond 1999; Tsigos and Chrousos 2002) – pulling the focus away from individual choices to the metabolic impacts of social stress.

Chronic illnesses such as diabetes significantly impact patients' emotional state and outlook because "illness becomes inseparable from life history" (Kleinman 1988:8). People with chronic illness address their condition on an ongoing basis so that their personal identity and health status overlap. However several studies have found that stress and depression in adults with diabetes are linked to metabolic function specifically associated with the disease, and are not simply complications of living with a chronic disease. Lustman and associates (1992:1631) argue that the risk for depression among people with diabetes "may vary as a result of disease-specific psychological and biological factors". Gary and colleagues (2000) found that depressive symptoms among African-Americans with type 2 diabetes were significantly associated with sub-optimal total cholesterol and triglyceride levels. In another study, Mooy and associates (2000) found that chronic psychological stress was associated with both undetected type 2 diabetes and central obesity, indicating that stress may be a causal factor in diabetes. Grandinetti and colleagues (2000) also reported that depressive symptoms were associated with glycemic control for both people with and without a prior diagnosis of diabetes. They (2000b:1444) assert that "stressful life events of chronic psychological stress are associated with glucose intolerance".

Population-based research into the relationship between chronic stress, central obesity, and diabetes was sparked by findings from the field of psychoneuroendocrinology. Bjorntorp, Holm, and Rosmond (1999) have developed a theory which states that environmental factors, including psychosocial and socio-economic stress, lead to the activation of the hypothalamo-pituitary-adrenal axis which results in a variety of endocrine abnormalities affecting insulin resistance and

contributing to central obesity, leading to type 2 diabetes. Tsigos and Chrousos (2002) have published similar findings, linking stress, metabolic function, insulin resistance, central obesity, and ultimately type 2 diabetes.

Considering these findings and considering the social suffering endemic to many aboriginal communities in Canada (Rock 2003, Adelson 2001) many researchers have looked into a possible link between suffering, stress, and diabetes in aboriginal peoples. Daniel and colleagues (1999) found a correlation between glucose intolerance and social environmental stress. They compared glycosylated hemoglobin levels between five different populations: Australian Aborigines, Torres Strait Islanders, First Nations Canadians, Caucasian Australians, and Greek migrants to Australia. They found that aboriginal indigenous populations all had higher glycosylated hemoglobin levels than the Caucasian Australians and Greek migrants to Australia, controlling for age, gender, glycemic status, anthropomorphic measures, fasting glucose, and 2-hour glucose concentrations. They argue that the stress of acculturation and not simply the stress of social change and adaptation contributes to glucose intolerance. The population of Greek migrants experienced social change upon migration and yet did not depend on "external resources compromising their autonomy as a people" (Daniel et al 1999:409). Loss of land, social functioning, autonomy, and economic activities is a type of social change unique to colonized indigenous peoples.

In a related study, Daniel and associates (2001) studied the impact of quality of life, mastery, and depression on lipid levels in people with impaired glucose in Aboriginal communities in the Okanagan district of British Columbia. They found that quality of life and mastery were positively related to HDL-cholesterol ("good"

cholesterol) levels, and depression was negatively related to HDL-cholesterol levels. They also found that lifestyle behaviour was not related to HDL-C, suggesting that emotional factors such as quality of life, mastery, and depression affect metabolic control are mediated by endocrine variables.

Rock (2003) argues that research on diabetes in aboriginal populations would benefit from a better understanding of the lived experience of diabetes and more specifically of the depression, stress, and suffering experienced by many aboriginal people with diabetes. The symptoms of diabetes as defined by biomedicine are hyperglycemia, increased urination and thirst, and the presence of complications such as ischemic heart disease and nephropathy. However, the lived experience of diabetes often includes one or more psychiatric disorders such as mood swings, and inability to concentrate (Rock 2003:149). Rock (2003) proposes that duress and stress, manifesting themselves in the form of depression and other psychological disorders, are not complications of diabetes, but rather have a causal nature.

3) Diabetes Complications

Every one of my informants with diabetes mentioned diabetes complications and/or premature death from diabetes. They were all concerned about the long-term consequences of their diabetes. Some felt that by taking care of themselves (through diet, exercise, and/or medication) they could reduce their chances of experiencing negative diabetes outcomes. Of these people some had a certain amount of optimism for the future, whereas others felt more anxious about possibly developing complications. However not all people believed that they could alter the course of the disease. "If you're gonna get sick, you get sick", as one man who had diabetes for several put it.

Research suggests that optimal control of blood glucose levels can reduce the likelihood of diabetes complications (The Diabetes Control and Complications Trial Research Group 1993). All of the practitioners I spoke with believed that through vigorous self-management and/or close observation and care diabetes complications could be avoided. As one physician put it, “you don’t have to die from it”. A few times practitioners mentioned the importance of educating people with diabetes about the complications of diabetes to encourage them to take the disease seriously and initiate self-management practices. Indeed one person with diabetes told me that she started taking the disease and self-management more seriously when she learnt about diabetic foot complications. However reminding people who are already well aware of the serious complications of diabetes may be counter-productive, sparking fear and hopelessness. These “tactics” should be delivered carefully and considerately.

4) The Patient-Practitioner Relationship

I found that patients and practitioners had different expectations and understandings of their relationship. Both patients and practitioners felt that the person with diabetes has most of the responsibility for diabetes management. This is sometimes interpreted that the practitioner must somehow convince the person with diabetes to take that responsibility and to undertake strict self-management practices. Thus the role of the practitioner is to counsel the person with diabetes. A successful practitioner successfully “gets” their patients to follow their recommendations. One approach to gaining compliance is to create a “partnership” where together both parties work on ensuring daily management guidelines are followed. This often turns into a method whereby the practitioner creates a relationship with the patient so the patient feels as though he or she

should follow the recommendations out of courtesy to the health professional. This approach may not be fruitful, as none of my informants with diabetes discussed the desire for a “partnership” with their physicians, nor did they suggest that wanting to please their physician, even in the case where the individual was satisfied with their physician, influenced their self-management practices.

Baker and Daigle (2000) found that the Mi’kmaq patients they spoke with were shy about asking for clarification from their health care providers. They did not want to “cause trouble”. One physician told me, “Some of my favourite patients are Native. They are happy with so little”. This might suggest that these First Nations clients are simply too shy to question the doctor. However none of the people with diabetes with whom I spoke mentioned that they were shy to ask their doctor questions. The main barriers to querying practitioners were lack of time and perceived practitioner openness. To locate the circumstances where Aboriginal patients ask few questions within individual bodies and psychologies, instead of within the broader social context of health care where practitioner time is highly valued and scarce and where Aboriginal people face racism and misunderstanding is simplistic.

People with diabetes wanted basic things out the patient-practitioner relationship. They did not speak of trust or reciprocity. They wanted two things – to be “looked at” and “listened to”. This is similar to the “affirmative” encounters of the First Nations women Browne, Fiske and Thomas (2000) interviewed. These women were satisfied with the medical encounters where they had opportunities to ask questions. The people I spoke with had very basic expectations of their physicians. They resented that physicians often did not have enough time to “look at” them or “listen to” them. In these cases

people felt as though their personal needs and concerns were not addressed, but rather the health care system's perception of their needs and concerns. When patients feel as though they are neither listened to nor looked at, they do not believe that the physician is doing an adequate job or cares sufficiently about their health. Patient discourse reflects the gaze back on to the practitioner, reminding them that they too have a role in diabetes management. Patients felt that they were primarily responsible for diabetes management but looked to their practitioners to "listen" and "look" – signs that they cared and signs that they were doing their best to help treat the diabetes. These expectations of care providers – thorough examination and open communication - do not appear to be especially culture-bound and a lack of understanding of First Nation culture should not be a barrier for appropriate practitioner care.

It is difficult to say how these different viewpoints of the patient-practitioner relationship actually affect the clinical encounter and diabetes care. Perhaps each party just wants some outward signs that the other is committed to managing and treating the disease.

An element of the patient-provider relationship is the interpretation of who is responsible for what. As previously mentioned, patients and providers felt that the majority of diabetes care was the responsibility of the person with diabetes. Both parties spoke of the importance of individuals taking responsibility for their health and their future. Practitioners spoke of the frustrations of convincing people with diabetes to "lose weight for them". To ease their frustration practitioners ought to remember that:

Failure to achieve and maintain weight loss may not be indicative of noncompliance but may be more reflective of the difficulties of losing weight when coupled with the altered metabolism of diabetes. (Brown et al 1996:613)

Many people with diabetes likewise criticized other people with diabetes for “cheating” and not taking their condition seriously. However the message of individual responsibility became complicated when people with diabetes spoke of the challenges of invoking self-discipline in their own lives. They agreed that they should watch their diets and stress levels and try to get regular exercise. As much as they believed that they should do these things they talked about the difficulties of following diabetic lifestyle recommendations given social pressure to eat, demands on their time, the expense of special diabetic foods, and the simple fact that they grew tired of depriving themselves. This is similar to Hunt and associate’s (1989) findings that people with diabetes understood what self-care practices they should follow but had difficulty implementing these changes into their complex worlds. Wanting to engage in optimal self-care and being able to consistently perform acts of great self-discipline while confronted with numerous obstacles are different things entirely. Therefore “convincing” people with diabetes to “take better care of themselves” may be fruitless act. It is not a matter of convincing it is a matter of enabling. This supports Anderson and Funnell’s (2000) assertion that the notion of compliance in diabetes can be harmful and counterproductive.

It is interesting to note that there were many similarities between the explanatory models of patients and practitioners. According to Kleinman’s theory of explanatory models, the differences between the models give us clues into how the medical encounter and medical outcomes can be improved. However similarities show the common ground between patients and practitioners, they reveal the influence of medical knowledge on how people and communities understand and cope with disease. They also reflect a “shared knowledge” of diabetes. Since my informants with diabetes agreed with many of

the tenets of diabetes education and treatment, the areas of disagreement (the role of emotions in diabetes management, the efficacy of medication, and the patient-practitioner relationship) are striking. These disagreements signify the “last frontier” of the adoption of biomedical knowledge. Here medical knowledge is challenged and changes take place in terms of how medicine approaches and understands disease.

Part 2: Institutional Issues

Racism

Both practitioners and people with diabetes talked about racist treatment of First Nations people within the health care system. People with diabetes discussed how racist attitudes affect the treatment they receive. Firstly they talked about feeling unwelcome in health care institutions outside of their community. Long waits, preferential treatment, and outright animosity on the part of health care workers made people with diabetes feel unwelcome. Like in Shirley-Spiers' (1989) study, First Nations patients felt as though they were objects to be processed through the hospital system, rather than people to be treated.

Considering the frustrations people with diabetes bring with them into the health care setting - the emotional difficulties associated with diabetes, the challenges of managing it, and issues with access to care - it is not surprising that poor treatment seemed to have a significant effect on people with diabetes. Certainly, many people brought it up. People saw the irony of feeling worse after visiting a place dedicated to healing. Another aspect of racist treatment people mentioned was mistreatment. Informants with diabetes tended to think that they received poor provider care in certain locations outside of their community due in part to their ethnicity. People complained of

“not being looked at”, or of being given diagnoses and prescriptions without doing tests. They thought that their concerns were not given due consideration because they were aboriginal. O’Neil (1989) and Shirley-Spires (1989) found similar perspectives among the aboriginal people with which they worked.

Health care administrators outside of the community indicated that aboriginal people in the area might receive “racist” treatment in that the treatment and advice given does not take into consideration people’s financial and community situations and overestimates the resources they have available (such as community home care and transportation). This was corroborated by the interviews with people with diabetes where people discussed the financial and social constraints of obtaining and following medical care. Browne, Fiske and Thomas (2000) also found that health care workers disregarded their First Nations patient’s personal circumstances.

Health care administrators also discussed the communication barriers between non-aboriginal health care providers and aboriginal clients. These include the tendency to talk fast and use eye contact which can be considered aggressive and inappropriate behaviours in aboriginal populations. Kelly (2002) also notes that this behaviour, which is appropriate in the general population, may hinder care providers working with aboriginal peoples. In an off-the-record discussion with a health care administrator who works closely with aboriginal patients, it was this person’s opinion that health care providers do not require specific education about generalized aboriginal communication styles and health practices. It was this person’s opinion that listening and respecting aboriginal patients is the most “culturally appropriate” care. Thus health care administrators differed in their understandings of why some health care providers do not

deliver appropriate care. Some believed that it was due to cultural insensitivity or lack of cultural knowledge, while others maintained that it was due to a lack of basic respect and caring. Therefore the current debate between about whether certain care is culturally insensitive or outright racist (Cully 1996) exists even within the small sample of this study.

Aboriginal people in Canada bear a much greater health burden than the general population (Young et al 2000). In addition throughout Canada aboriginal people have a higher usage of health care (Waldram, Herring and Young 1997). Since aboriginal people have certain benefits that the general population does not (non-insured health benefits and often free medical transportation) the higher use rates are understood in terms of taking advantage of the system. This is a reflection of the stereotypes about aboriginal people that prevail across the country. It is not surprising that the attitudes of some care providers are impacted by cultural stereotypes and misinformation so that the high health care services use of aboriginal peoples becomes read as misuse and abuse of health care services.

Racism and inappropriate treatment are additional barriers to health that aboriginal people with diabetes must manage. Not only does racism within the health care system breed mistrust of patients, but also it is an additional form of stress. The intricacy of managing stress and emotional upheaval has already been addressed. From that argument it is clear that additional social stress in the form of racism and differential treatment impedes healing and diabetes management. Moreover racism within the health care system may lower clients' expectations. I was told that many aboriginal patients expect very little. My informants with diabetes sought and desired high quality care and

fair treatment but were not surprised or outraged when they did not receive it. Considering First Nations people have suffered a legacy of unfulfilled expectations and dashed hopes for decades in a post-colonial context the fact that their attitude comes across as having low expectations is understandable.

I was unable to obtain any interviews with physicians at the nearby hospital. I tried to contact them on several occasions and proposed a variety of different interview methods so they could choose the most convenient and agreeable one. I was eventually contacted by one physician and was told that none of the physicians would be available to do an interview with me because they were too busy during working hours seeing patients and when the workday was over they did not want to discuss work. As such I was not able to get their perspective and a better understanding of the conditions at the hospital.

I cannot say whether racist attitudes and behaviour exist at the nearby hospital or whether they are simply perceived to exist. However claims of racist behaviour should not be too easily dismissed. As O'Neil (1989) reminds us, seemingly innocent behaviour on the part of health care providers can easily be interpreted as racist given the history of health care provision for aboriginal people and the current political climate. Perceived racism and "real" racism have the same negative effects and must both be dealt with and managed. The community health committee has plans to address these issues at a regional level and develop culturally appropriate practice guidelines and methods of addressing incidences of racism. This is a sensitive area, which the community health committee is determined to address with tact and openness.

Health Care Choices and Satisfaction with Care

Considering that they may be faced with racism in the health care system, health care choices were important to people with diabetes. In theory community members with diabetes do have a choice of health care provider but considering medical transportation is only provided to the nearest hospital, their choice is limited. If people had the time and money to go beyond the nearest facility, which is another hour or so by car, and if these physicians were taking new patients, they would have more choices. Limited health care choice is a reality that low income and isolated communities face. Limited choice is compounded in communities, such as the study community, which is both low income and isolated.

Limited health care choice has two consequences. One is the impact on health outcomes. People with diabetes who have a positive relationship with their providers tend to have better outcomes (Helseth et al 1999, Dietrich 1996). Indeed, both health care providers and people with diabetes discussed the impact of the relationship (in terms of trust and communication) on health outcomes. People with diabetes spoke about the relationship in terms of mistrust, lack of communication, and resultant unacceptable recommendations and treatment path. Providers talked about how building positive relationships with people with diabetes enhances trust, compliance, satisfaction, and outcomes. The people with diabetes in this study overwhelmingly were not satisfied with their primary care physicians and could not communicate, trust, and/or agree with their physicians. The second consequence of limited health choices is that such lack of choice reinforces the notion of Aboriginal docility and lack of control over their health and their future.

Health Care Services

For Canadians with treaty status, health care services are comprised of two levels of organized medical services, universal health care and an additional level of health services paid for by the First Nations Inuit Health Branch of Health Canada. These additional health services are either managed by FNIHB or by a tribal council health authority as in the case of the study community. I will describe how the hospital environment and patient management system affect the way patients approach the clinical encounter. Then I will describe how the additional bureaucracy that aboriginal people face exacerbates the issue of seeking care.

People with diabetes frequently discussed the hospital atmosphere and organization. Above I reviewed the issue of racism and how perceived racism by the hospital staff affected people with diabetes. For some people, racist treatment discouraged them from seeking care, while others continued to seek care despite the treatment they received. However people also complained of the general atmosphere in the hospital. They said it was uncomfortably cold and unwelcoming. They complained of the long waits – up to two hours even when they did have an appointment. Lazarus (1988) explains that these features of institutions – long waits, discomfort, and cold atmosphere – set the stage for the clinical encounter. These features instill the fact that decisions are made by and for the institution. They are “nodes of discipline”, to use a Foucauldian (1995) term, where bodies are made docile and power-relations reinforced. Ironically, these nodes serve to disempower the patient while physicians are taught to empower patients to give them the tools to self-manage. These conflicting messages confuse and confound people.

Issues of access to care, limited practitioner choice, and racism compound the effect of the institutional atmosphere. Many people with diabetes use the medical van service where they are picked up at a designated time and returned home several hours later. They sit for hours in a cold waiting room, worried about the possibility of being confronted with racism. They finally see a doctor with whom they probably do not have a good relationship and are seen briefly. If any tests are required, a nurse does them. If the patient is lucky, he or she is referred to a specialist several hours away and in a few months must arrange for a bus ticket or gas money to travel to see the specialist, who may or may not communicate the test results. During all of these interactions they have very little control, but when they go home they are expected to exert tight control over their lifestyle choices and ultimately blood sugar levels. This is demoralizing for patients. As Lazarus (1988) found, these procedures make people feel processed rather than helped, creating additional nodes where bodies are made docile. Physicians have a difficult task to encourage and support people with diabetes who seek care within a system that gives them few choices or signs of hope and encouragement.

My key informants strongly believed that provincial health care services for people with diabetes should be offered on reserve. People in the community were often nervous about going outside of the community for individual or group care. This may be somewhat related to perceptions of racism, but also due to familiarity and comfort in one's own community. Henderson and associates (1995) also found that First Nations people with diabetes generally felt uncomfortable receiving care outside of their community. They did not feel at ease being "the only Indian there" (Henderson et al 1995:64).

Key informants were given many reasons why these health care services could not be provided on reserve, but found none of them satisfactory. They believed that it was simply a matter of money. They felt that the provincial government did not want to commit to providing more services on-reserve because that would set a precedent and pave the way to providing additional provincial health care services on-reserve. They suspected that the government was thinking "Well, if we give you this, then what next?". I propose that much of the health care provided to people First Nations with diabetes has this underlying fear. What next? As a response to this fear strict rules are drawn and bureaucracies expanded to ensure that those who receive care know exactly what they are entitled to and are discouraged from asking for more. Bureaucratic mazes and cold institutions discourage these people from asking for more or from expecting more. I think there is an underlying message that the services they already receive are a privilege and will be taken advantage of if not closely monitored. This concept, this suspicion, grounded in the historically rooted dependency relationship between government and aboriginal peoples in Canada, influences policy, institutional settings, and even the clinical encounter. Rather than expanding services to address the worsening health status of Canadian aboriginals, services that were once offered to aboriginal people have been discontinued. FNIHB once provided shoes for people with diabetes and funded a foot nurse program, but these services have been rolled back. Other services currently received can be withdrawn at any time. These factors impact how people see themselves and their care. My informants reacted to the restrictions and considered them unfair, unwise, inefficient, unhealthy, and even racist.

Chapter 6: Conclusions

Diabetes care for First Nations communities is complex. Diabetes care takes place in hospitals, health centres, health education offices, specialists' clinics, people's homes, schools, and communities. The people involved include nurses, doctors, dietitians, family members, clergy, health care administrators, community health representatives, medical van drivers, grocery store owners, neighbours, and most importantly, the people with diabetes themselves. Some places and faces are friendly, others strange. People with diabetes navigate through these different locations, interacting with different people, while themselves dealing with the complex and difficult emotional and physical impacts of the disease.

How can we make sense of this anthill of activity? We have seen that the day-to-day logistics of managing diabetes, the institutional atmosphere, the institutional restrictions, the emotional complications of diabetes, and patient-practitioner interaction all impact diabetes care and ultimately diabetes outcomes. Where are we to focus our attention? Which factors seem to have the greatest impact on diabetes outcomes? Which factors can actually be realistically improved? Before these questions can be answered, we must map out the multi-factoral nature of diabetes care.

I propose that a model of diabetes care must start with the person who has diabetes. This is not an attempt to localize a multi-factoral and highly dynamic system within an individual body. However each node of diabetes care links to the individual. The individual is the pathway between the different nodes. Of course diabetes care is ultimately aimed at individual bodies and it is individual bodies that suffer and understand the disease uniquely. Thus at the centre of the model is the person with

diabetes. After my conversations with people with diabetes, I believe that people with diabetes approach care wanting (a) day-to-day living to be as comfortable as possible and (b) to avoid diabetes complications. The people with whom I spoke do want to control their blood sugar to prevent future complications, although they also do not want to suffer from mood swings, deprivation, family tension, and social deprivation on a daily basis. Thus for most people with diabetes it is not either/or. It is instead a delicate and pragmatic balance. They are always looking towards an uncertain and fearful future, while managing immediate health and well-being concerns. This is the person at the centre of our model. This is not a person whose psychology must be understood and tweaked. This is not a person who just needs more education.

The person with diabetes lives within a constellation of factors that influence diabetes care – both self-care and institutional care. These influences include access to care, efficacy of treatments, logistics of self-management, delivery of services, health care policies, relationships with health care providers, and social influences.

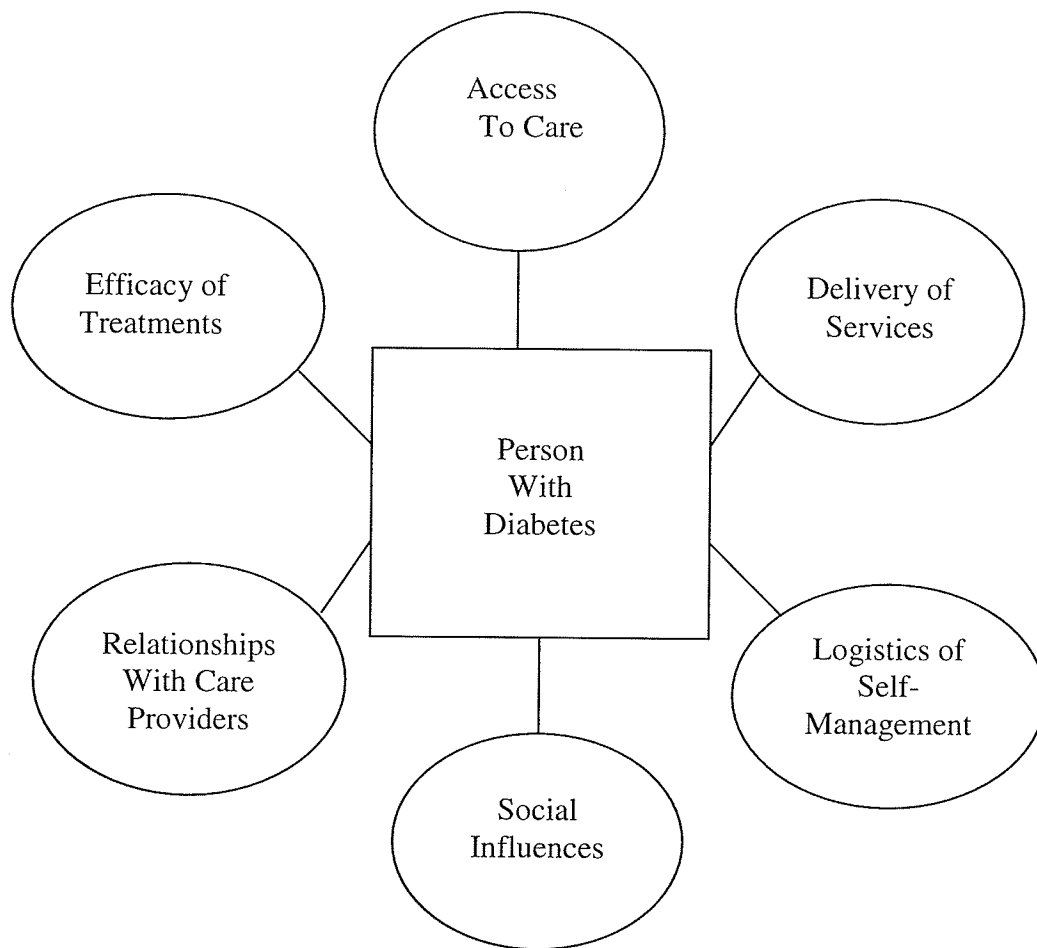


Figure 1: Proposed Diabetes Care Model

Diabetes care should focus on both short and long-term outcomes because they both impact the experience of diabetes and diabetes care. However, considering the multitude of long-term issues that can demoralize and discourage people with diabetes, ensuring that day-to-day living with diabetes is manageable is integral. Those people who had difficulty living with diabetes on a daily basis and constantly felt they were battling the disease were aware of future possible complications, afraid of these complications, but used all of their resources to maintain daily functioning. Maintaining daily functioning ranges from managing stress levels, trying to put healthy food on the table without too much resistance from family members, finding time to exercise amidst social and family obligations without recreational services available, to facing a hostile environment while trying to seek care. It is my position that people with diabetes must be first supported in their struggles to develop successful daily management. This means that those influences on the figure above that assist people in their immediate care must be given top priority. This will help the person with diabetes attain some success and become emotionally and physically ready to manage for the future. In addition it will develop patient-practitioner trust. A treatment plan that is acceptable to both the patient and practitioner must first be developed. I spoke with many people who did not take their medication because it made them feel worse or because they were suspicious of it. Some flexibility and experimentation in terms of treatment plan is required on the part of practitioners.

The logistics of self-management also greatly impact the experience of daily management. Helping people with diabetes identify and work on the barriers to daily management is necessary. It is likely that this would be most successful at the local level,

using resources already available. Diabetes education sessions currently focus on the details and mechanics of food choices and blood sugar monitoring. Including discussions about the barriers to performing these mechanics would be helpful to both people with diabetes and practitioners. From these discussions, resources that would help people with diabetes in their daily management may be identified. My informants had various ideas, such as forming exercise groups, group shopping and cooking, and peer support groups. Diabetes education should also be expanded to include the role of stress in diabetes. Resources to help people with diabetes manage their stress levels and other emotional issues associated with having diabetes should also be made available.

The last category of immediate concern I believe is ensuring that acceptable care is made available to people with diabetes. It is unacceptable that the only care available to people with diabetes is by practitioners who are seen as uncaring, uncommunicative, and with questionable knowledge in an institution that is deemed racist and unwelcoming, and at a distance. It is also troubling that due to economic and bureaucratic reasons people with diabetes and many health care providers and community members have not been able to find alternate solutions.

By addressing First Nations people with diabetes' immediate concerns about their health and well-being, health care providers will be able to provide more effective and acceptable care. In addition, people with diabetes will feel respected and listened to. This will serve as a partial antidote to the negative impacts of institutional alienation and bureaucratic restrictions that take decision-making power and patient confidence away. However this means shifting the focus from education and compliance and fear of long-term complications to day-to-day management and health to lead develop long-term

health. This kind of approach understands that people live, struggle, and laugh within the contexts of their families and communities and must delicately balance the demands of life with those of diabetes care and management.

Meanwhile, more investigation should be made into how institutions and bureaucracies impact the way in which people view and use the health care system and more importantly understand their own health and health care. First Nations people are faced with excessive bureaucracy, institutional alienation, and racism. These obstacles to health should not be perceived as macro-level backdrops, but reinvented and recreated realities formed by actors in the health care system, both aware and unaware of the ramifications of their actions. Through understanding how these institutional and jurisdictional obstacles are developed and maintained, First Nations communities and organizations will perhaps be able to reform how health care for First Nations people is conceived and managed. In addition looking more closely at institutional and jurisdictional barriers to health give researchers a better understanding of how the micro and macro interact and cohabit.

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Appendix A

Consent Form

Perspectives of Diabetes Care Research Project

CONSENT TO PARTICIPATE IN A STUDY

I, _____, agree to participate in the above titled research project. The purpose of the project is to explore the understandings of the quality of treatment and care for diabetes of health care workers and persons with diabetes in the community.

The study is being conducted by Leigh Hayden, a graduate student of Anthropology at the University of Manitoba, under the guidance of Sharon Bruce, Ph.D, Department of Community Health Sciences and Department of Anthropology. The study has been approved by the University of Manitoba's board on ethics involving research on human subjects (HREB).

I understand that my participation involves participating in a brief survey and interview. It will take approximately 2 hours. The survey will ask me questions about the extent of my involvement with diabetes treatment while living in the community. I will also be asked to supply demographic information for comparative purposes. This survey information will be anonymous. I will be asked to participate in an interview where I will be asked questions about my experience and outlook on the quality of diabetes treatment and care in the community. The interview will be tape-recorded. I will be given a code and this code will be used so the information in the surveys can be linked to the information in the interview. I have been assured that all survey information will be combined and compressed to preserve my and others' identity. I have also been assured that any identifying information given in the interview will be withheld so my identity will remain anonymous.

The survey will be completed at my home or the health centre, whichever I feel more comfortable in. My participation is voluntary and I may withdraw from the study at any time by simply telling the researcher. If I feel tired and wish to stop completing the survey or interview or prefer to continue at a different time, that is fine. I may also refuse to answer any questions. I can receive answers to my questions about the study at any time.

I understand that Leigh Hayden can be called at (204) _____ if I have further questions about the study. I can also contact her advisor, Sharon Bruce at (204) _____, or the Margaret Bowman, chairman of the Human Ethics Research Board at (204) _____ if I have any questions or concerns.

Again, I understand that I am free not to answer any particular question and that I can withdraw my participation and interview from the project at any time without any disadvantage to myself.

I agree to participate in this project. Oral Consent €

Your signature _____ Date _____

Interviewer's signature _____ Date _____

copy 1 to participant

copy 2 to interviewer

Appendix B

Interview Schedule

Interview Schedule

Questions for People With Diabetes

The following questions are designed to find out about your experience, concerns, and understandings about the care people with diabetes in your community receive. Please remember that you can choose not to answer any of the questions. You also can stop the interview at anytime.

- 1) Please tell me about the diabetes management advice health care practitioners have given you.
- 2) What are your thoughts about the care you are receiving for diabetes treatment?
- 3) How much of diabetes management do you see is your responsibility, and how much is the health care provider's responsibility?
- 4) Tell me about your relationships with the people who have treated you for diabetes.
- 5) What advice can you give health care practitioners who treat diabetes?
- 6) How can your diabetes be improved?
- 7) Where do you receive treatment for diabetes?

Questions for Health Care Practitioners

The following questions are designed to find out about your experience, concerns and understandings about the care provided to people with diabetes in the study community. Please remember that you can choose not to answer any of the questions. You also can stop the interview at anytime.

- 1) Please tell me about the kind of care provided to people with diabetes in the community.
- 2) How can diabetes care provided to people in the community be improved?
- 3) How can diabetes management be improved in the community?
- 4) Do any health care services need to be made more available to people with diabetes? If so, which ones? How would any improved availability ultimately impact the health of patients?
- 5) How much of diabetes management do you see is your responsibility, and how much is the patient's.
- 6) Tell me about your relationships with the people you treat for diabetes.

- 7) What advice can you give people with diabetes?

Questions for Health Care Administrators

The following questions are designed to find out about your experience, concerns and understandings about the care provided to people with diabetes in the study community. Please remember that you can choose not to answer any of the questions. You also can stop the interview at anytime.

- 1) What, in your opinion, are the barriers to diabetes care in the community?
- 2) How can diabetes care be improved in the community?
- 3) Do any communication barriers exist between health care providers and patients? If so, please explain.
- 4) Do any communication barriers exist between health care providers inside and outside of the community? If so, please explain.