

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

BY

LEIGH GRACE HAYDEN

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
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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)