DIABETES-RELATED FOOT COMPLICATIONS AND AMPUTATIONS IN A MANITOBA FIRST NATION COMMUNITY: A SYSTEMS APPROACH TO PREVENTION

by

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A Thesis
submitted to the Faculty of Graduate Studies of
The University of Manitoba
in partial fulfillment of the requirement for the degree of

MASTER OF SCIENCE

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Winnipeg, Manitoba

THE UNIVERSITY OF MANITOBA

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To the late Dr. George Louridas
for his remarkable vision and commitment to improving the lives of his patients

and

To the people of the community who endured foot complications and amputation
for their courage and their time in sharing their stories.

ACKNOWLEDGEMENTS

This research would not have been possible without Dr. Sharon Bruce, my advisor, who guided this work from inception to dissemination. Thank you Sharon for your time sharing the foundational ideas in this work, for giving me the space to grow with this project, and for your friendship.

I thank the members of my thesis committee: Dr. John O'Neil for his insights and perspective on health and people, Dr. Evelyn Forget for her kind guidance and her mentorship in policy application, and Dr. Susan McClement for her generous support in the final stage of dissemination. Special thanks also to Dr. Joe Kaufert and to Dr. Pat Kaufert for their kindness and encouragement throughout my graduate program. I feel privileged to have been a part of this rich research environment at the Department of Community Health Sciences.

I feel especially lucky to have met the people in the community who invited me into their homes and gave this work meaning. I thank the members of the community Diabetes Research Working Group for their commitment and ongoing interest in working together on the problem of foot complications and amputation.

Thank you to my dear parents, Sachitha Attawar and Yeshwanth Attawar, for nurturing my passion for learning and for the sacrifices they made towards my education.

Finally, I am indebted to my husband, Greg Tonn, for his unfailing support and love. Thank you Greg for your example and for bringing music to my life every day.

ABSTRACT

The prevalence of lower-extremity amputation, one of the most serious and costly complications of diabetes, is considerably higher among Manitoba First Nations relative to the general population. Considerable variation in prevalence of diabetes exists between Manitoba's First Nation communities. A case study of diabetes foot care involving in-depth interviews with multiple stakeholders of diabetes care was conducted in one First Nation community in Manitoba in a region with one of the highest rates of amputation in the province.

Major factors contributing to poor foot health outcomes included provider practice, participation of people, coordination of care, availability of health services, access to care, funding structures, policy and jurisdiction. Significant structural factors underlying the problem of foot complications and amputation included: the lack of provision of regular foot examinations, lack of timely referral to specialist physicians, crisis work conditions, and restrictive footwear policy.

The conclusions of the study support a foot care strategy that incorporates both systems change, toward improved integration and coordination of foot care systems, and policy change, toward more equitable allocation of health resources. The information gathered in this study serves as a tool for one First Nation community's governance of foot care.

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CHAPTER ONE

INTRODUCTION

1.1 SUMMARY

Type 2 diabetes mellitus (DM2) is an epidemic in many of Canada's First Nation populations, and is steadily increasing in prevalence globally. The disease appears to have a multifactorial etiology and results from a combination of genetic, behavioural and environmental factors. Individual level risk factors of diabetes such as diet and physical inactivity have been well established in the scientific literature. Structural, environmental level factors that may influence lifestyle are not as well documented.

The public health significance of diabetes is manifest in associated microvascular and macrovascular complications including heart disease, stroke, peripheral vascular disease, peripheral neuropathy (foot pain, foot ulcers, and lower-extremity amputation) as well as disorders of the eyes (vision impairment and blindness) and kidneys (renal failure) (Lee et al., 1993; Meltzer et al., 1998; Narayan, 2002; Nelson et al., 1988). In addition to the human cost, diabetes-related complications contribute significantly to the high economic cost of the disease. In Manitoba, higher per capita health care costs among First Nations persons with diabetes compared to persons with or without diabetes in the general population have been attributed to higher health service utilization. This may largely be explained by higher rates of hospitalization and correspondingly higher rates of diabetes-related complications (Dow, 1992; Jacobs et al. 2000; Martens, 2002). Persisting, poor health outcomes and high health care utilization costs associated with complications of DM2 among Manitoba First Nations reflect potential gaps in health services and the need for more effective secondary prevention strategies.

Complications of DM2 are major contributors to morbidity and mortality and affect Aboriginal people[1] disproportionately. Lower-extremity amputation rates are especially high among Manitoba's First Nations relative to the general population. Considerable variation in diabetes prevalence and presentation occurs between First Nation populations in Canada, and has been attributed levels of acculturation and genetic factors (Young et al., 1990). In Manitoba, diabetes prevalence among First Nation communities varies according to geography and income (Martens et al., 2007). Diabetes prevalence is conspicuously higher among First Nation communities in southern Manitoba than in the more remote northern communities (Green et al., 2003, Martens et al., 2007). Patterns of health care use among First Nations in Manitoba, however, do not appear to consistently reflect the high rates of diabetes and diabetes complications in these communities. Registered First Nation people living in the southwestern communities of the Dakota Ojibway Tribal Council in particular, have the highest diabetes treatment prevalence (25%) and the highest rates of diabetes-related amputations in the province, yet also have the lowest rate of specialist consult visits (0.21 visits per person per year) (Martens et al., 2002). Specialist consult rates were found to be inversely associated with amputation rates, in a recent study of First Nation communities in Manitoba, suggesting that access to health services plays an important role in foot health (Martens et al., 2007).

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[1] The Canadian Constitution identifies three groups of Aboriginal Canadians: First Nation (status and non-status), Inuit and Métis.

Few studies in the literature have closely examined the relationship between health care services and health outcomes in Canada's First Nations communities. In the current transition toward First Nation managed health services, there remains a need for systematic documentation of community resources and health service structure to provide vital baseline information for more optimal management of diabetes-related complications.

In order to gain a better understanding of why First Nation communities in the south are more vulnerable to diabetes foot complications and amputations, a case study of foot care was conducted in one First Nation community in a region of southern Manitoba with one of the highest rates of diabetes and diabetes-related amputation in the province. In-depth interviews were conducted with multiple stakeholders of diabetes care including nurses, physicians, health administrators and individuals with diabetes foot complications and amputations working and living in the community. Using a systems approach, the structural factors impacting poor foot health outcomes were deconstructed and the underlying relationships between these factors were analyzed. The problem of foot complications and amputations was explored in the context of the health system and the broader social, economic and political environment surrounding foot care. The information gathered in this study provides a foundation for the development of a comprehensive diabetes foot complications prevention strategy in one First Nation community.

1.2 PURPOSE

Goals and Objectives

The purpose of this research study was to explore in one Manitoba First Nation community, the structural factors associated with foot complications and lower-extremity amputation. The specific objectives of the study were:

1. To document the resources and health services available for diabetic foot care in the community.
2. To identify the barriers that affect diabetic foot care in the community from the perspective of multiple stakeholders.

Research Questions

1. What is the extent of the problem of diabetes-related foot complications and amputations in the community?
2. How is the current health care system functioning in the management of diabetes-related foot complications?
3. What factors contribute to high rates of diabetes foot complications and amputations in the community?
4. How can the delivery of diabetes-related foot care in the community be improved?

CHAPTER TWO

REVIEW OF LITERATURE

2.1 TYPE 2 DIABETES

Diabetes has a global distribution and is estimated to affect over 100 million people worldwide (King, Aubert, & Herman, 1998). In Canada, nearly 1.5 million people, or 5% of the population, were diagnosed with diabetes by 1995 (Tan & MacLean, 1995a). This number is expected to grow to 3 million by the year 2010 (Tan & MacLean, 1995b).

Diabetes mellitus defines a diverse group of metabolic disorders characterized by high plasma glucose concentrations (Expert Report 1997). Type 2 diabetes mellitus (DM2) accounts for the majority of cases of diabetes, and is characterized primarily by defects in insulin secretion and insulin resistance in the major peripheral tissues (Matthaei et al., 2000). The clustering of insulin resistance and hyperinsulinemia with other known cardiovascular risk factors suggest that these metabolic defects may play a key etiological role in the development of chronic disorders including obesity, hypertension, diabetes, dyslipidemia and atherosclerosis (Zimmet, 1993). Type 2 diabetes represents the final stage of a chronic, progressive syndrome caused by varying combinations of insulin resistance and decreased pancreatic B-cell function (Matthaei et al., 2000). Hyperglycemia develops gradually in this disease and often goes undiagnosed for many years. Nevertheless, individuals with DM2 have an increased risk of developing macrovascular and microvascular complications. The risk of developing DM2 increases with age, obesity and lack of physical activity.

Type 2 diabetes is a disease of multifactorial etiology resulting from the complex interaction of genetic susceptibility, and behavioural and environmental factors (Neel et al., 2000b). The major risk factors associated with diabetes are genetic factors, perinatal factors, obesity, diet, and physical inactivity (Narayan, 2002; Young et al., 2002). Physical inactivity and obesity have been identified as important risk factors for diabetes. The role of dietary factors, however, has not been consistently demonstrated (Young et al., 2000b). The large variation in the prevalence of DM2 in different ethnic groups provides indirect evidence of a genetic predisposition to this disease. Genetic susceptibility to the disease is unmasked by rapid change of environmental/lifestyle factors. Multiple genes (loci) interact with each other and also with environmental factors in the development of DM2 (van Tilburg et al., 2001). Genes may play a role during any of the metabolically distinct stages of DM2. A comprehensive understanding of the genetic component of DM2 is complicated by the genetic heterogeneity of populations, the complex interactions between multiple genes, and the modulating role of the environment in disease expression (Busch & Hegele, 2001).

2.2 TYPE 2 DIABETES IN CANADA'S FIRST NATION POPULATION

Type 2 diabetes mellitus has currently reached epidemic proportions in many of Canada's First Nation populations, who are at an increased risk of the disease (Young et al., 2000b). The age-adjusted prevalence of diabetes among First Nation men (11%) and women (16%) is 3.3 and 5.3 times higher respectively than among other Canadian men and women (First Nations and Inuit Regional Health Survey National Steering Committee, 1999).

In Manitoba, there has been a steady rise in the prevalence of diabetes among adults since 1991 (Blanchard et al., 1996). The First Nations population of Manitoba, which constitutes approximately 100,000 or 9% of Manitoba's 1.14 million people, exhibits a higher prevalence of diabetes than the general Manitoba population in all age groups (Jacobs et al., 2000). The age-adjusted prevalence of diabetes was estimated to be 2.86 times greater in Registered First Nation men than non-First Nation men, and 4.64 times greater in Registered First Nation women than non-First Nation women in Manitoba in a study based on physician and hospital claims from the Manitoba diabetes database (Green et al., 2003). The overall age and sex-adjusted diabetes prevalence of Manitoba First Nation people living on-reserve (203 per thousand) was reported to be 4 times higher than all other Manitobans (45 per thousand) according to a study based on administrative claims data linked with federal Status Verification System files (Martens et al., 2007). In addition, there is an alarming trend in Manitoba's First Nation populations toward earlier age at onset of DM2 (Dean, 1998; Dean, Mundy, & Moffatt, 1992).

Complications of diabetes have emerged as significant contributors to the disease burden experienced by First Nations peoples resulting in poor health outcomes including disability, a compromised quality of life, and premature death (Brassard, Robinson, & Lavallee, 1993; Brassard & Robinson, 1995; Macaulay, Montour, & Adelson, 1988; Young et al., 1989; Young et al., 2000b). Aboriginal women residents on reserves appear to have more than a five-fold risk of death from diabetes compared with the general

Canadian population (Mao et al., 1992). In addition to duration of illness, factors significantly associated with the presence of complications in Canada's Aboriginal populations include coexisting hypertension (Mao et al., 1992; Young et al., 1985)age, BMI (Schulz et al., 1997), poor glycemic control and elevated triglyceride levels (Brassard et al., 1993). The increasing prevalence of DM2 among Canada's Aboriginal children is of particular concern (Dean, 1998; Sellers & Dean, 2000; Harris, Perkins, & Whalen-Brough, 1996). Individuals with early onset DM2 have an increased duration of disease and therefore a greater likelihood of developing serious microvascular and macrovascular complications during young adulthood (Young et al., 2000).

Epidemiologic studies of diabetes among Canada's First Nations populations document distinct patterns of geographic variation of the disease suggesting an interplay of genetic susceptibility, levels of acculturation and specific risk factors in its etiology (Young et al., 1992). Prevalence of diabetes among Canada's First Nation population has been shown to vary according to language group, culture area, geographic location or latitude and degree of isolation. These determinants are associated with several factors including the degree of Euro-Canadian influence on Aboriginal lifestyle change, the degree of contact with broader Canadian society, and genetic relationship (Young et al., 1990). The wide range of prevalence of diabetes within Canada's First Nation populations occurs both nationally (Young et al., 1990) and regionally (Pioro, Dyck, & Gillis, 1996)in diabetes prevalence, age of onset, and male/female ratios exist even between communities of the same tribal background in close proximity (Delisle & Ekoe, 1993; Hood et al., 1997; Pioro et al., 1996). Interestingly in Manitoba, First Nation communities in the southern rural areas of the province have a much higher incidence and prevalence of diabetes than First Nation communities in the more remote northern rural areas of the province (Green et al., 2003; Martens et al., 2007). In addition to geographic variation, diabetes prevalence in Manitoba First Nations has also been strongly associated with income level. Higher average household income within tribal council areas was associated with lower diabetes prevalence revealing the importance of socioeconomic determinants of health in this population (Martens et al., 2007). The significant diversity in disease presentation between First Nation communities reinforces the need for diabetes prevention initiatives to be tailored to the specific needs of each community.

Evidence supporting a genetic contribution to the development of DM2 in North American Aboriginal populations has been demonstrated by various studies investigating admixture effects, twins, familial clustering, candidate gene screening, and genome wide scanning (Busch et al., 2001; Hanis et al., 1996; Hanson et al., 1998; Hegele et al., 2000; Kahn, Vicent, & Doria, 1996; Knowler et al., 1990; Matthaei et al., 2000; Schraer et al., 1988; van Tilburg et al., 2001). The striking variation in prevalence of diabetes between Aboriginal populations in Canada suggests that, in addition to genetic background, environmental factors such as diet and level of activity may play a major role in determining disease susceptibility (Hegele, 2001). Obesity and physical inactivity are considered ‘modifiable' risk factors, and are believed to be the main nongenetic determinants of the disease. A reduction in the risk of type 2 diabetes has been demonstrated by changes in the lifestyles of high-risk subjects (Tuomilehto et al., 2001). Obesity and physical inactivity are now prevalent in many Aboriginal populations (Harris et al., 1997; Young & Sevenhuysen, 1989).

2.3 DIABETES RELATED FOOT COMPLICATIONS

Foot complications, the “forgotten complications” of diabetes (Ulbrecht, Cavanagh, & Caputo, 2004), are becoming an increasingly common problem throughout the world. Diabetic foot ulcers affect an estimated 25% of individuals with diabetes during their lifetime. Nonhealing foot ulcers precede amputation in 84% of all cases of lower-extremity amputation in patients with diabetes (Reiber, 1996). Rates of amputation in diabetic individuals are generally higher in males than females and increase with advancing age. Approximately 6 to 30% of individuals with amputation will have a second leg amputation within one to three years of their initial amputation. Diabetics who have undergone amputation commonly experience serious comorbid conditions. Mortality in amputees is usually the result of cardiac or renal complications. The mortality rate of diabetics after lower-extremity amputation ranges from 11 to 41% by 1 year, 20 to 50% by 3 years, and 39 to 68% by 5 years (Reiber, 1996).

Foot complications of diabetes encompass a large number of heterogeneous conditions which include foot ulcers, acute injuries, and soft tissue infection (O'Rourke et al., 2002). Peripheral neuropathy and peripheral vascular disease contribute significantly to the development of foot and ankle ulcers. Patients with arterial ischemia have poorer outcomes, higher amputation rates and lower healing rates than those with non-ischemic disease (O'Rourke et al., 2002). Risk of foot ulceration also increases with long duration of diabetes, prior history of ulcer, high foot pressure, poor metabolic control, tobacco smoking, age and low socioeconomic status. Late presentation of foot complications is also associated with a poor prognosis (Reiber, 1996; O'Rourke et al., 2002; Urbancic-Rovan, 2005).

Peripheral neuropathy is one of the most common complications of diabetes and consists of several neuropathic syndromes. The development of neuropathy is associated with cardiovascular risk factors as well as with increasing age, increased duration of diabetes, poor glycemic control, retinopathy, albuminuria, and vascular risk factors. The pathogenesis of diabetic neuropathy is not completely clear. Nerve damage has been linked to axonal loss, demyelination of nerve fibers, and reduced density of myelinated fibers. Chronic hyperglycemia has been strongly implicated in the pathogenesis of diabetic neuropathy. Microvascular disease does occur in some cases of diabetic neuropathy and is correlated with the severity of neuropathy (Tesfaye, 2006).

Distal symmetrical neuropathy, synonymous with the term "diabetic neuropathy", is the most common type of neuropathy and the main initiating factor for foot ulceration. Pathology may involve sensory, motor or autonomic nerves. Sensory nerve involvement is characterized by the loss of sensation in a stocking distribution that progresses cranially from toes to legs. Clinical symptoms vary in severity and include numbness, tingling, pain (that is more severe at night), cramping, and sensations of hot and cold (Tesfaye, 2006). Neuropathy is often insidious in onset and can go unnoticed (Urbancic-Rovan, 2005). Some individuals with neuropathy experience no symptoms until the onset of a foot ulcer. Patients who have lost protective sensation are at high risk of developing mechanical and thermal injuries (Tesfaye, 2006). Loss of protective sensation allows skin injury to occur without pain and can lead to foot ulcers and infection (Ulbrecht et al., 2004).

As the disease advances, motor neuropathy can occur causing muscle weakness, atrophy, foot deformity, altered foot biomechanics and leading to increased foot pressures when walking or standing. Skin breakdown usually results from cumulative pressure loading over time rather than a single step on a sharp object. Some individuals with neuropathy have such high plantar pressures they can ulcerate with just a few steps walking barefoot. Pressure points result in callus formation and thinning of sub-metatarsal head fat pads. Deformities such as a bunion or in extreme cases Charcot arthropathy, a gross disorganization of the bones of the foot, can form the focus of ulceration. With advanced neuropathy, sensory ataxia can occur causing unsteadiness when walking increasing the risk of falls. Autonomic neuropathy results in altered regulation of cutaneous blood flow and loss of sweating leaving the skin dry and vulnerable to cracking, and predisposing the patient to infection (Tesfaye, 2006; Urbancic-Rovan, 2005).

Atherosclerotic peripheral vascular disease is a major factor in the progression of foot pathology in patients with diabetes. Atherosclerosis of the peripheral arteries contributes to poor perfusion of the extremities. The diabetic foot is more susceptible to small changes in perfusion than the nondiabetic foot and therefore has a greater sensitivity to occlusive atherosclerosis. Atherosclerosis is four times more prevalent in diabetic patients and progresses at a more rapid rate than in the nondiabetic population. Atherosclerotic disease is characterized by claudication, rest pain and tissue loss. Claudication occurs due to proximal arterial occlusion and is an important early sign of peripheral vascular disease. Decreased blood flow to large muscle groups causes ischemic muscle pain. Rest pain which is usually described as "burning pain" is indicative of severe occlusive disease. Tissue loss occurring as a result of foot ulceration or gangrene is the most severe presentation of vascular disease. Infection associated with ulceration and gangrene tends to be aggressive and is often polymicrobial in patients with diabetes. Infection can therefore cause significant tissue destruction and is the most common cause of amputation in the diabetic foot (Dinh & Veves, 2006).

Amputation thus results from the interplay of peripheral neuropathy, microvascular changes, macrovascular changes and infection in patients with diabetes. Peripheral neuropathy leads to structural and sensory changes in the diabetic foot making it vulnerable to injury without protection. Injuries are not often detectable and heal slowly. Dry skin, loss of protective sensation, high foot pressures and deformity all can lead to skin breakdown, infection and ultimately amputation. Skin breakdown leads to infection. Microvascular and macrovascular changes deter healing (Ulbrecht et al., 2004; Dinh et al., 2006).

2.4 DIABETES-RELATED FOOT COMPLICATIONS IN CANADA'S FIRST NATION COMMUNITIES

Limited information is available regarding foot complications among Canada's Aboriginal population. Young and colleagues (1985) reported the overall prevalence of neuropathy to be 6% among thirty First Nation communities in northwestern Ontario and northeastern Manitoba in a study based on a chart review (Young et al., 1985).

More recent studies have shown foot complications of diabetes to be highly prevalent in First Nation communities. The age and sex-adjusted rate of amputation for Manitoba First Nations living on-reserve (3.39 per thousand) was reported to be 18 times higher than for all other Manitobans (0.19 per thousand) (Martens et al., 2007). In this study, amputation rates were shown to be inversely associated with access to specialist care, but not income or geography. Tribal council areas with lower consult rates had higher rates of amputation.

Factors in the health care environment were also implicated in the occurrence of foot complications among First Nation and Métis people in a remote northern community in Canada (Reid et al., 2006). In this cross-sectional, cohort study, based on interviews, physical examination and retrospective chart reviews, the authors reported a high prevalence of diabetic foot complications (82% of participants) associated with substantial morbidity in this community. Foot problems accounted for a significant proportion of hospital visits including 18% of local emergency room visits and 16% of hospitalization days by residents. Yet, many residents had inadequate footwear (33%), and few foot exams were performed (0.7 screening foot exams per diabetic per year) .

Foot complications have been recognized as a significant problem among Aboriginal youth in Canada. In a study conducted in a tertiary care, hospital diabetes clinic and two remote outreach clinics, a high prevalence of foot abnormalities was observed in First Nation and Métis adolescents with DM2 including neuropathy (12%), based on interview or chart review, as well as poor toenail conditions (49%) and calluses (44%) based on examination (Chuback et al., 2007). Foot complications in this group were significantly associated with absence of running water in the home, decreased frequency of bathing, decreased frequency of nail clipping, and provision of foot care by an older individual. Despite having had significantly more specialist consultations, adolescents living in First Nation communities had a similar prevalence of foot complications to urban adolescents. The authors speculated that without specialist involvement, a higher prevalence of complications might have been observed among the former group.

The profile of amputation for Aboriginal people differs from that of non-Aboriginal people in Canada. In a study based on interviews and chart reviews at a tertiary care hospital, First Nation and Métis people with amputations, living in rural and First Nation communities in Manitoba and northwestern Ontario, were found to have a higher incidence of comorbidity than rural, non-Aboriginal people with amputations. Aboriginal people with amputation had greater difficulty with mobility outside the home and were less likely to use a lower prosthesis than non-Aboriginal people with amputation (Meatherall et al., 2005). Lower-extremity complications including osteomyelitis, Charcot foot, foot ulcers and amputations were observed more frequently among Aboriginal than non-Aboriginal diabetic patients with end-stage renal disease. While both groups lacked adequate footwear, Aboriginal patients had less access to home care services compared to non-Aboriginal patients (McIntyre et al., 2007).

2.5 HEALTH SERVICES IN CANADA'S FIRST NATION COMMUNITIES

2.5A ORGANIZATION OF HEALTH SERVICES

The First Nations and Inuit Health Branch (FNIHB), formerly known as the Medical Services Branch (MSB) of Health Canada, remains the main government body in Canada responsible for Aboriginal health services. Some aspects of Aboriginal health are included in the functions of the Public Health Agency of Canada, created in 2004 as a separate entity from Health Canada (Wien & McIntrye, 1999; Wardman, Clement, & Quantz, 2005). FNIHB funds and administers health services for registered First Nation and Inuit persons within a regional structure comprised of zones that roughly correspond to the boundaries of the provinces and territories, with the exception of the Atlantic Region. Services are typically delivered via health centres, nursing stations, clinics and a small, declining number of hospitals in Aboriginal communities within each zone (Wien et al., 1999).

Nurses formed the core of health service delivery in Aboriginal communities. Hospital-based and community health nurses constitute the largest group of health professionals in public service under the umbrella of FNIHB. Nurses working for FNIHB, particularly those employed in remote posts in the north, faced increased occupational responsibilities with minimal support and direction. The cross-cultural setting and geographical isolation in Aboriginal communities created challenging work conditions for health staff (Waldram, Herring, & Young, 2006). Nurses working in these communities encountered additional issues of power and control within the government bureaucracy, medical dominance and community pressures (Waldram et al., 2006).

Physicians occupied most senior management positions until the late 1970s when they were replaced by administrators with little or no health background. Facing a serious shortage of physicians in the late 1960s, FNIHB contracted out physician services in northern zones to universities. The University of Manitoba Northern Medical Unit occupies a unique place in the delivery of Aboriginal health services in Canada as the only remaining university program. This program, which eventually expanded to encompass more than thirty communities in Manitoba and Nunavut, has established extended contractual relationships with provincial and territorial governments (Waldram et al., 2006).

The involvement of Aboriginal health care para-professionals in the delivery of primary health care services was supported by the creation of the Community Health Representative (CHR) Program by FNIHB in the early 1960s. In 1978, First Nation communities were able to hire their own CHRs through contribution funding agreements. The role of the CHR in communities has undergone significant changes. Initially marginalized within the health system and the community, CHRs received little training and were given token duties. More recently, CHRs have received improved training and are able to engage in a wide spectrum of curative and preventive activities from dispensing antibiotics to promotion of healthy lifestyles. In some cases, CHRs provide clinical services in smaller communities without resident nurses. The role of CHRs has been somewhat redefined as part of the health transfer initiative and has shifted more towards community health and education activities (Young et al., 1992; Waldram et al., 2006). Direct Aboriginal participation in the provision of health services through initiatives such as the CHR program has been credited for bridging communication barriers and improving the quality of Aboriginal people's experiences with health care (Young et al., 1992; O'Neil, 1993).

Aboriginal health care in the north is characterized by widely dispersed communities that are isolated from one another and from larger urban medical centres. Primary care services in these communities range from well equipped nursing stations staffed with specialized outpost nurses to more modest health stations run by local health auxiliaries with varied levels of training and experience. CHRs and nurses have an expanded role in remote communities, providing both curative and preventive services. These front-line workers have varying degrees of support from visiting physicians, dentists and other health professionals. Substantial health care resources are used for the transfer of patients, including emergency and elective cases, from these remote communities to urban hospitals (Young, 1981; Young et al., 2000a).

Currently, many First Nation communities access health services from a local health centre. Health centres offer a variety of public health and treatment services delivered by nurses and local CHRs (Lavoie, 2003). However, most health institutions on-reserve are funded to provide only a limited number of health promotion and prevention services. In contrast, nursing stations are able to provide a more comprehensive range of primary health care services (National Aboriginal Health Organization, First Nations Centre, & First Nations Information Governance Committee, 2005).

2.5B FINANCING OF HEALTH SERVICES

Health care services in First Nation communities are funded under dual jurisdictions. Most health services delivered through health centres in the community are funded by the federal government. Physicians who visit communities on a regular basis are paid by the province. Patients requiring emergency care, specialist care or other tertiary services are transported, with federal funds, to the nearest hospital or medical centre which is under provincial jurisdiction (Lavoie et al., 2003).

The Aboriginal Diabetes Initiative (ADI), one component of the Canadian Diabetes Strategy, is one source of federal funding for diabetes services among Aboriginal people. The ADI provides funding for First Nations living on-reserve in three areas: (1) diabetes care and treatment services, (2) diabetes primary prevention and health promotion activities, and (3) lifestyle support services to help those living with diabetes and their families cope with the disease. The ADI was designed to improve access to diabetes care, treatment and support services, to improve diabetes awareness and implementation of effective diabetes prevention programs, and to strengthen community-based organizations that support participation in diabetes programs (First Nations and Inuit Health Branch Working Group, 2007).

2.5C UTILIZATION OF HEALTH SERVICES

Regional patterns of health service use among Canada's First Nations do not appear to consistently reflect the high disease burden of these populations. In Alberta, despite the increased prevalence of asthma and COPD in the Aboriginal community, First Nation people with these respiratory disorders were less likely to see a specialist or receive spirometry testing of pulmonary function than the general population in Alberta (Sin et al., 2002). In Saskatchewan, the prevalence of psychiatric disorders is estimated to be 80% higher among the First Nation population than among the non-First Nation population. Despite this, Saskatchewan First Nation people had lower rates of outpatient treatment for every psychiatric diagnosis except alcohol/addiction disorders, and were less frequently admitted for all psychotic disorders than the general Saskatchewan population (Fritz & D'Arcy, 1982). In Manitoba, Registered First Nations people, despite their relatively poor health status, have much less contact with specialist physicians (0.90 visits per person) in comparison to the general population (1.28 visits per person). In fact, Manitoba First Nation communities with some of the highest premature mortality rates and highest diabetes complication rates appear to have some of the lowest rates of health care use (Martens, 2002).

A few studies have documented structural barriers facing Aboriginal populations in Canada. Key barriers reported in an urban Aboriginal population include a lack of information available on health care resources, a lack of health care services and programs, limited access to traditional health services, negative and stereotypical attitudes of health care providers, and lack of sufficient translation services for Aboriginal languages (Shestowsky, 1995). Canada's remote First Nation communities face special health care challenges including: (1) economic barriers such as poverty, unemployment, a shortage of adequate housing, and limited availability or affordability of healthy food choices; (2) organizational barriers including a shortage of trained professionals and specialized care frequently resulting in relocation to urban centres for medical intervention; and (3) jurisdictional barriers resulting in a lack of coordinated care and service disparities (Schmidt, 2000; Young et al., 1989).

2.5D HEALTH TRANSFER

The process of self-determination in Aboriginal health care as we see it today emerged out of the new Indian Health Policy, adopted by the federal government in 1979 (Waldram et al., 2006). This policy, still relevant today, recognizes three pillars of Aboriginal health: (1) community development, (2) the traditional trust relationship between Indian people and the federal government, and (3) the interrelated, multisectoral Canadian health system (Health Canada, 1999). These principles provided a basis for increasing involvement of Aboriginal communities in health planning and led to the development of two community-based health initiatives, the Native Alcohol and Drug Abuse Program and the Community Health Demonstration Program (Garro, Roulette, & Whitmore, 1986). The Indian Health Policy was as an official recognition by the Canadian government of the resistance to 'colonial medicine'(O'Neil, 1993).

Health transfer for First Nations actually began with the Community Health Demonstration Program (CHDP) created by MSB in 1982. This plan, involving thirty-one projects across Canada, was intended to allow First Nations to experiment with different models of delivery and control of health care(Young et al., 1992). The mixed experience of one community in southern Manitoba with the CHDP was representative of First Nations who participated in the process (Garro et al., 1986). This community was able to initiate a disease prevention program, undertake a community household survey, establish a local health advisory committee and a health coordinator position, refine administrative policies and develop a consultative relationship with MSB. However, the community also experienced several problems during the Program. Community members were less engaged in preventive measures than in treatment services. The community and MSB were slow to accept the role of the health coordinator. The health committee and newly hired health staff needed time to realize their roles. The Demonstration Program did not allow sufficient time to recruit, train and mobilize staff. Garro and colleagues (1986) were critical of the planning and implementation of the Demonstration Program. They maintained that the Program was developed without formal input from Aboriginal organizations. In addition, only communities funded under the Demonstration Program became eligible for transfer of health services to local control

(Garro et al., 1986). CHDP projects yielded valuable insights for participants, but slowed down transfer initiatives for Bands that were not involved (Young et al., 1992).

The Health Transfer Policy was first announced in 1986. Health transfer refers to the transfer of 'control' of existing on-reserve health services in First Nation communities from FNIHB to First nation authorities, and the devolution of responsibility for health care from federal to territorial governments(Young et al., 1992; O'Neil, 1993). Although the intention of the federal government is to decrease its role as the direct provider of services to First Nations, transfer of health services remains entirely optional (Lavoie et al., 2003).

The Health Services Transfer Program, the most popular form of transfer, was designed to allow First Nations to develop control slowly over the delivery of health services in four phases. During the initial Pre-Transfer phase, the First Nation establishes a health management structure, a health needs assessment and a community health plan. The second Bridging phase involves a negotiation process. During the third Implementation phase, the First Nation implements the health plan and delivers agreed-upon services. In the final Reporting phase, the First Nation produces an annual report on programs delivered and undergoes an evaluation every five years (Health Canada, 1999; Waldram et al., 2006). Services eligible for transfer are defined by the federal government and include mandatory services such as communicable disease control, environmental and occupational health and safety programs, and treatment services. Medical and Hospital Insurance Services (provided under provincial jurisdiction) as well as some Non-Insured Health Services including medication, medical transportation, eye care and dental care are not included (Health Canada, 1999; Lavoie et al., 2003).

Two alternatives to the transfer model were introduced by the federal government in order to accommodate different levels of development. The Integrated Community-Based Health Services program, created in 1994, allowed First Nations the option of signing one Contribution Agreement to administer select community health services. The Inherent Right to Self-Government Policy, created in 1995, gave First Nations the opportunity to reconcile all government funding agreements under one framework agreement (Waldram et al., 2006).

By 2002, 81 per cent of eligible First Nation communities were actively involved in the health transfer process in some way (Waldram et al., 2006). The program appeared to be highly successful. However, many concerns and criticisms of the process continue to be raised.

During the early years of transfer, First Nation leaders expressed reservations about the program. In 1988, the Assembly of First Nations alleged that transfer initiatives were designed to further the agenda of the federal government to reduce spending on Aboriginal health, and thereby abdicate its legal and fiduciary responsibility for the delivery of health care services to First Nations. Viewing devolution of health services in terms of decolonization, O'Neil noted that that little real empowerment of regional health boards occurred during transfer of authority for health to territorial governments (O'Neil, 1993). Culhane Speck (1989) argues that the Transfer Policy did not demonstrate a significant change in the federal government's position in First Nations health. She suggests that transfer policy was an attempt by the federal government to shift its legal responsibility for Aboriginal health to provincial governments. Culhane Speck noted that limited block funding of transferred services offered First Nations communities little flexibility in meeting the needs of residents. Communities, Culhane Speck predicted, would be faced with the difficult task of "choosing between the lesser of two evils", such as choosing between maintaining necessary curative services or supporting preventive and educational programs (Culhane Speck, 1989).

Many concerns were raised about the appropriateness and equity of funding for transferred services. First Nations services did not appear to be funded on an equitable basis compared to provincial services when heath inequities and cost of delivery were taken into account (Lavoie, 2004). A national evaluation of the Health Transfer Policy undertaken by the Centre for Aboriginal Health Research of the University of Manitoba indicated that funding for transfer and integrated agreements has been based on a mix or historical and per capita based funding which has led to inequities. Levels of funding have not kept with price/volume, population growth and needs. (CAHR, 2005). As an adjunct to the evaluation, a recent study comparing transferred communities with health centres revealed variations in transfer funding across Canada (Lavoie, 2007). Manitoba and Atlantic First Nation communities had the lowest levels of funding compared to other regions. In fact, Lavoie (2007) found that First Nation communities that entered the transfer process early had access to less funding per capita than those who transferred more recently. In addition, per capita funding levels for communities did not correspond to program responsibilities incurred under the transfer agreement according to the study.

CHAPTER THREE

METHODS

3.1 STUDY DESIGN

3.1A GENERAL DESIGN

A case study of foot care was conducted in one community. The case study approach, using one-on-one interviews, enabled an in-depth exploration of the experiences of stakeholders with diabetes-related foot complications and with the health care system. Smaller cases – the stories of people – are nested within the larger case of the community.

This study was developed as an adjunct to the *Manitoba First Nations Diabetes and Diabetes Complications Screening Study* (here after referred to as the Diabetes Complications Screening Study) headed by Dr. Sharon Bruce. The Diabetes Complications Screening Study was a part of the Interdisciplinary Health Research Team (IHRT) Diabetes Project titled *Diabetes in the Aboriginal Population: Defining, Understanding and Controlling an Emerging Epidemic,* led by Dr. Kue Young. This project was undertaken as a partnership between universities and First Nation communities in Manitoba, Ontario, and Quebec. The IHRT diabetes projects in Manitoba received considerable support from key stakeholders including the Assembly of Manitoba Chiefs, the Manitoba First Nations Diabetes Working Group, the National Aboriginal Diabetes Association, and ten First Nations communities.

3.1B COMMUNITY PARTNERS

A community based participatory research framework was used to guide this study. The value of a participatory research approach has been demonstrated in several diabetes research studies in Aboriginal communities (Macaulay et al., 1998; Herbert, 1996; Boston et al., 1997; Watson et al., 2001). The fundamental principles of community based participatory research are: (1) collaboration, (2) equity, (3) community development, and (4) action (Minkler & Wallerstein, 2003). Community based participatory research is community-driven and begins with an issue of importance to the community. It engages all partners in a cooperative process, allowing each partner to share knowledge and experience in an equitable manner. It fosters development of systems and builds capacity in the local community. Finally, it seeks to use knowledge and "action for social change" to improve the health of community members (Minkler & Wallerstein, 2003). This study was conducted in collaboration with one First Nations community in southern Manitoba. A community Diabetes Research Working Group, formed as part of the Diabetes Complications Screening Study, was an integral partner in the research design and process. The Working Group is composed of members of the community health authority including administrators, nurses who provide diabetes care in the community, as well as core members of the community diabetes team. The Working Group identified diabetes-related foot complications as a priority, upon receiving preliminary results from the Diabetes Complications Screening Study, and supported the launch of this study in order to examine the problem in greater detail.

The data gathered in this study are centred on the experiences of individuals who lived with diabetes-related foot complications and amputations in the community. This study has supported the building of local knowledge and capacity in the community in several ways. During the course of the study, the principal researcher served as an education resource to the community by participating in education workshops that addressed the prevention and management of diabetes-related foot complications. Provider focus group meetings, organized as a part of the study, facilitated continuing education of providers. These meetings also created opportunities for primary care providers and specialists to build stronger networks.

3.2 CONCEPTUAL FRAMEWORK

3.2A DETERMINANTS OF HEALTH

Robert Evans and Greg Stoddardt's classic model of health (1994) serves as a useful framework for understanding the relationships between health determinants. This model builds on the health field concept introduced in the 1974 Lalonde report, *A New Perspective on the Health of Canadians*, which emphasized the centrality of the objective of health and categorized the determinants of health into four fields: lifestyles, biology, environment, and health care organization. The concept of health is further expanded in the Evans and Stoddardt model. In this model, distinctions are made among disease, as defined by the health care system, health and function, as experienced by individuals, and well-being, a much broader concept of individual life satisfaction. The authors acknowledge that health can have different meanings for different individuals, and suggest that multiple concepts of health can exist in a continuum. For example, as the authors point out, medical definitions of disease and patient experiences of illness do not necessarily always correspond.

The Evans and Stoddardt model (1994) offers a critical perspective of the health care environment, questioning the primacy of the influence of the health care system on health. Health care is conceptualized as having a direct impact on disease but not on health and function which the health system is seen as influencing only indirectly. In this model, health care is viewed, not as an end in itself, but as a means to good health in concert with other determinants.

A broad range of factors, beyond the health care environment and beyond the realm of the individual, is recognized in the model as having an impact on the health of individuals and populations. The model allows for a more complex understanding of individual behavioural and biological responses that are seen as shaped by social and physical environments. The social environment can influence biological response via input to the nervous system. Genetic endowment interacts with social, cultural and physical environments to determine individual response. Whether genetic predispositions or resistances are expressed as disease will depend on various environmental factors. The response of the individual, which includes the decision to seek and comply with care, influences the ability of the individual to resist illness and also affects the burden of disease. The interactions between these determinants are viewed as critical to the health of individuals and populations (Evans & Stoddardt, 1994).

3.2B HEALTH PLANNING

The Precede-Proceed model for health promotion planning and evaluation is a comprehensive framework for planning and evaluating health programs (Green & Kreuter, 1999). The model uses an ecological approach addressing both behavioural and environmental factors impacting health. The Precede-Proceed model takes into account the multiple determinants of health, and assists in the process of distilling those factors into a highly focused subset in order to identify targets for intervention. In a progressive, sequential narrowing of focus, priorities identified in the planning phase of the Precede framework become goals and targets in the implementation phase of the Proceed framework. The model has been applied in planning strategies to address risk factors for Type 2 diabetes in a Canadian Aboriginal community (Daniel & Green, 1995).

The Precede-Proceed model consists of a continuous series of nine phases in planning, implementation and evaluation. The first four phases make up the Precede planning framework. Phase 1, the social assessment, identifies the social problems a community experiences as a practical measure of quality of life. In Phase 2, the epidemiological assessment, one specific health problem most in need of change and linked to the social problems in phase 1 is selected.

Assessment of the determinants of the health problem occurs in phases 3 and 4 of the model. In phase 3, the behavioural and environmental assessment, specific behavioural and environmental factors linked to the health problem are identified. The behavioural assessment first involves identification of risk factors associated with the health problem. Risk factors are then assessed in terms of importance, based on prevalence and strength of association with the health problem, as well as in terms of changeability. Risk factors are then ranked in terms of importance and changeability to identify program priorities. The environmental assessment focuses on risk conditions that contribute to health problems. This assessment prioritizes aspects of the social environment that are changeable by social action and health policy. Environmental factors are then analyzed and ranked according to relative importance and changeability.

In phase 4, the educational and ecological assessment, determinants are analyzed and grouped into three broad categories: predisposing factors, reinforcing factors, and enabling factors. Predisposing factors include knowledge, attitudes, beliefs and values that facilitate or deter motivation for change. Enabling factors are the skills, resources or barriers that can influence behavioural or environmental change. These factors include the availability and accessibility of resources. Reinforcing factors are the rewards or feedback received from adopting a behaviour and include, for example, the attitudes and behaviour of others. These factors are then ranked according to their relative importance and the possibility of change. The phases of the Precede model lay the foundations for program planning.

Phase 5, the administrative and policy assessment, signals the transition to the Proceed component of the model. In this phase, political, organizational and administrative capabilities and resources for the development and implementation of a program are analyzed. Phases 6, 7 and 8 are the implementation and evaluation phases of the Proceed framework.

3.2C SYSTEMS ORIENTATION

A systems approach is defined as “a paradigm or perspective that considers connections among different components, plans for the implications of their interaction, and requires transdisciplinary thinking as well as active engagement of those who have a stake in the outcome to govern the course of change” (Leischow & Milstein, 2006). The fundamental principle of a systems orientation to health and health care is an emphasis on relationships between structures. In this relational approach, the interconnectedness of different types of structures such as biological, organizational and political systems is explored. Such relationships are recognized as complex and non-linear. Understanding the nature of systems also requires an understanding of how people interact with each other (Leischow & Milstein, 2006).

Holistic, non-reductionistic thinking is a central aspect of the systems perspective. Systems thinking incorporates both the analysis and synthesis of ideas. It requires both analytic thinking, in which the parts are first examined in order to explain the larger whole, and synthetic thinking, in which the containing whole is first examined and then disaggregated to explain the parts. In this perspective, the various parts of a system cannot be examined as discrete entities alone but must be seen as part of a larger whole in which they are intricately embedded and interconnected. Changes in one part can lead to changes among all parts and in the whole system itself. The performance of a system is thus the product of the interactions of its parts (Patton, 2002).

A systems approach is multidisciplinary. It encourages the gathering and integration of information from many different sources. It requires the exchange of information across organizational and academic boundaries, thereby linking different disciplines and preventing the occurrence of "silos" or disconnected respositories of information (Leischow & Milstein, 2006).

A systems perspective provides a practical way of framing a health problem as a part of a system of structured relationships. More than a paradigm shift, this approach also expands options for interventions. Understanding how systems are organized and how they behave over time, allows an understanding of how they can be better governed (Leischow & Milstein, 2006).

A systems approach has been applied to understanding the population health dynamics of diabetes. Health planners developed a systems dynamics model to explain the growth of diabetes and to predict the future burden of the disease in terms of morbidity, mortality and costs in the United States (Jones et al., 2006). This model depicts the movement of people into and out of four stages of disease in both diagnosed and undiagnosed states: normoglycemia, prediabetes, uncomplicated diabetes and complicated diabetes. In the model, potentially modifiable influences affecting rates of population flow through the stages of diseases were identified. These "flow-rate drivers" included: prediabetes and diabetes detection, prediabetes management, diabetes control and population prevalence of obesity. The model was used to generate a baseline simulation of future diabetes prevalence and mortality rates on the basis of survey data available for the adult population in the United States and estimates from the scientific literature. The impact of three possible policy intervention scenarios on the baseline scenario was then tested. Enhanced clinical management of diabetes, the first intervention scenario, resulted in a decrease in the rate of diabetes progression and deaths from complications. A small increase in the prevalence of diabetes also occurred. This effect is explained in the model using the analogy of the gradual filling of a bathtub with a slow drain. Interventions improving clinical management of diabetes reduce mortality rates (outflow), but without any reduction in the incidence of diabetes (inflow), also caused a "backing up" of diabetes cases. Increased management of prediabetes, the second intervention scenario, resulted in a small but significant decrease in incidence and prevalence of diabetes. The effect was small as the intervention did not reduce the actual onset of prediabetes. Prediabetes management did, however, more effectively reduce deaths from complications than did the diabetes management intervention. The third intervention scenario, reduction of obesity prevalence led to a decrease in the incidence of both prediabetes and diabetes. In addition, obesity reduction was able to stop and reverse the growth of diabetes prevalence and complications deaths (Jones et al., 2006).

The diabetes systems dynamic model conceptualizes the interrelationships between components of diabetes management systems and the impact of these components on the progression of diabetes. The model reveals several characteristic dynamics of the simulated diabetes population. Upstream interventions such as obesity reduction had a powerful influence on controlling prevalence of diabetes and diabetes complications. Diabetes management and control efforts had a limited impact on disease prevalence as it led to a "backing up" of cases. Health system interventions had varying short term and long term effects on disease patterns. Significant delays were observed between primary prevention efforts and downstream improvements in diabetes outcomes. The authors concluded that mixed diabetes intervention strategies would be much more effective in the long term than would single diabetes management scenarios in controlling the onset and progression of diabetes (Jones et al., 2006).

3.3 SAMPLE

The populations of interest in the study are the major stakeholders of diabetes foot care – people who lived in or were associated with the community, and had special knowledge of and experience with the problem of diabetes-related foot complications. A purposeful, non-representative sampling strategy was used to obtain a diverse selection of perspectives from a wide variety of individuals. Participants were also recruited through the assistance of local community members and staff at the community health centre. As the investigator did not have prior knowledge of the diabetes status of community residents, a community health nurse made the initial contact with community residents with diabetes to invite members of this group to participate in the study.

Key informants were selected from four groups: (1) community members who had experienced amputation and/or foot problems related to diabetes; (2) family members of community members who had experienced amputations and/or diabetes-related foot problems; (3) health care providers who provided the majority of diabetes care to community members for greater than three months, and (4) administrators from the community health authority. The principle investigator interviewed nine people living in the community, ten health care providers and five community health administrators for a total of twenty-four participants. The people in the community who were interviewed were individuals who had been diagnosed with diabetes and/or had experienced diabetes-related foot problems including lower extremity amputations, as well as family members of individuals with diabetes. Health care providers interviewed included nurses, primary care physicians, specialist physicians as well as allied diabetes care and foot care providers. The nurses interviewed were affiliated with several community health programs. Primary care physicians who participated in the study worked in the community and/or had practices based in one of two rural hospitals that served the community. Physician specialists interviewed included several vascular and infectious disease specialists based in an urban hospital setting.

3.4 DATA COLLECTION

Data was gathered in the community from 2003 to 2005. Two methods of data collection were employed. Semi-structured, one-on-one interviews were conducted with all participants. A questionnaire guide (See Appendix) was developed based on preliminary measures addressing: community assets, diabetes foot care management, structural barriers related to diabetes foot care (explored at a social, cultural, economic and political level), and the structure and organization of health care in the community. The questionnaire guide served as a starting point for stimulating discussion around experiences of living and managing diabetes and diabetes-related foot complications, as well as experiences with the health care system. Interview questions were open-ended and general in nature. Questions posed were dynamic and evolved as data gathered from initial interviews informed subsequent interviews. Interviews were conducted in person at the community health centre, at the residences of participants, and in hospitals where providers were based. Data from the interviews was recorded by audiotape and through field notes. Audio recordings of interviews were transcribed by the principal researcher and a transcriber. Follow-up interviews were conducted with some participants by telephone.

A review of historical and health documents was also conducted to provide contextual information about the community. Documents related to Band history, previous community health initiatives/surveys, records of existing health services/resources and health service use, as well as summary reports of diabetes and diabetes complication rates were reviewed. Relevant documents were identified upon the recommendations of participants.

3.5 DATA ANALYSIS

3.5A CONCEPTUAL ANALYSIS

Analysis of the data was conducted in three sequential phases. In the first phase, a conceptual analysis of the data was conducted. Data from individual transcripts were analyzed line by line and coded according to emerging concepts. Coded data were first compared within each participant group (community residents, nurses and allied health providers, physicians, and administrators) to identify common and divergent ideas. Key concepts were then tabulated according to participant group. Next, conceptual analysis of data was extended across participant groups. Issues that recurred among participants from several different groups were identified. Data were then regrouped and tabulated according to key issues. These issues were documented in text form and supported with direct quotations from participants.

The computer software program, NVIVO 2.0, was used to store, organize and link data. Coded transcripts were filed in word documents and organized into sets according to participant group, diabetes status, and foot complication status. During analysis of each line of text, sections of coded text were categorized into nodes according to key concepts or ideas. Text segments were simultaneously 'tagged' with descriptive annotations and stored as DataBites. Nodes were organized and reorganized multiple times as concepts, issues, themes and subthemes were added, rearranged and linked during the analysis. During the analysis, node structures were continually modified in a dynamic process as new themes and ideas were identified. Nodes and DataBites were examined within each document and within each document set allowing linking of concepts, issues and themes within and between participant groups.

Content analysis of documents was also completed. Information from evaluation reports, proposal reports, diabetes registers, and newsletters was reviewed. Relevant data from these documents was summarized and integrated into text in the results section. The results section in chapter four is the final product of the conceptual data analysis.

3.5B FACTOR ANALYSIS

In the second phase of analysis, the major factors contributing to the problem of foot complications and amputations in the community were identified. The Precede Proceed model of health promotion planning (Green & Kreuter, 1999) was used as a guide to define and prioritize major contributing factors. The Evans model of health (Evans et al., 1994) was used as a framework for conceptualizing the main determinants of foot health. Data were systematically grouped into three levels – individual level factors, health systems factors and broad determinants of foot health. Major issues raised by participants as impacting foot care and foot health were identified as subcategories within each level. The results of the factor analysis are summarized in Figures 1, 2 and 3.

Finally, in keeping with a systems approach, the relationships between contributing factors and foot health outcomes were examined. The interrelationships between health systems factors in particular were examined in greater depth. One of the major issues impacting foot health identified across several participant groups, the lack of provision of basic foot care, was explored revealing the interplay between underlying individual level factors, systems factors and broad determinants. The results of the analysis of factor relationships is summarized in Figures 4 and 5.

3.6 RIGOR

Several strategies were incorporated in the research process to ensure that the data collected were true representations of the experiences and views of stakeholders in the community. Triangulation was one approach used for verification. Data were gathered from several groups of key informants in order to capture multiple perspectives of the problem of diabetes-related foot complications. The study also involved multiple methods of data collection including both interviews and document reviews. Preliminary analysis findings of interview data were discussed with three participants in order to verify the meaning and accuracy of information gathered.

Peer examination by the supervising research advisor through debriefing sessions, review of transcripts as well as discussions regarding emerging themes provided an additional external check of the research process. The systematic tape recording of interviews and the use of one interviewer enabled consistent documentation of the perspective of participants and contributed to the dependability of results. Lastly, the extended time spent in the community (2003-2005) gathering information and participating in community health initiatives enabled the building of trust with stakeholders and the sharing of authentic experiences.

Standards of quality were adhered to in the following ways. The research questions served as the main impetus for this work driving both data collection and the analysis framework. The analysis process was made more robust through the use of classic and validated theory including the Evans & Stoddardt Model of health (1994), the Precede-Proceed Model (Green & Kreuter, 1999) and a systems dynamics model (Jones et al., 2006). The thesis attempts to present a balanced viewpoint of stakeholders allowing multiple voices across disciplines, genders, institutions to be heard. Finally, the thesis has practical value as the key barriers to foot health identified serve as a framework for health planning and policy development (Creswell, 1998).

3.7 ETHICAL CONSIDERATIONS

Strict measures were undertaken to ensure that the privacy of participants in this study was protected. The identity of the community was withheld in accordance with the wishes of community leaders at the inception of the study. All data was anonymized and kept confidential to protect the identity of participants. Tapes and transcripts were stored in a locked filing cabinet. Consent forms were stored separately from data in a secure location. Participants were identified only by study number in transcripts and analyzed data. Participants who have positions that may be easily identifiable were referred to only in general terms to maintain anonymity. The principal researcher reviewed only anonymized, aggregated health information such as that compiled for internal or external reports, and did not seek access to any personal health information or any records with personal identifiers.

In keeping with the principles of community based participatory research, this research is subject to the governance agreement developed jointly by Dr. Sharon Bruce and the Diabetes Research Working Group as part of the Diabetes Complications Screening Study. This governance agreement is consistent with principles of OCAP[2]. This agreement has received the approval of the Band Council. This project has also received the approval of The University of Manitoba Health Research Ethics Board.

3.8 LIMITATIONS

Although the information gathered in this study may serve as a resource to the community in which it is based, study results will have limited generalizability to other communities. The findings of this study may, however, be of some relevance to First Nation communities in Canada with a similar health service structure at a similar stage of health transfer.

While data collected were enriched through the use of a semi-structured approach and nonprobabilistic sampling methods, a larger sample size would further maximize variation of individual perspectives and add greater richness to the data gathered. The sample size was limited by the time available for data collection and analysis.

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[2] The principles of ownership, control, access and possession (OCAP) embody themes advocated by First Nations in Canada. Ownership refers to the relationship of the community to its cultural knowledge/data/information. The principle of control asserts that First Nations Peoples and their communities have the right to seek to control all aspects of research and information management processes which impact them. The principle of access refers to the right of First Nations communities to have access to information about themselves and their communities. Ownership identifies the relationship between the community and their data , and is distinct from possession (Scharch, 2004).

Finally, interpretation of this data is subject to the limitations of most qualitative research. As the researcher is the primary instrument of data collection and analysis in ethnographic research, final interpretation of the data remains the researcher's own representation. The researcher undeniably brings his/her own personal biases and experiences to the research process. The principle investigator's values and personal history as a clinician may have influenced the collection and interpretation of the data. Characteristics including the age, gender, education and non-Aboriginal status of the principle investigator may serve as potential sources of respondent bias.

CHAPTER FOUR

RESULTS

I. RESULTS OF DOCUMENT REVIEW

4.1 COMMUNITY PROFILE

4.1A. BACKGROUND

Location

The community is located in southern Manitoba, 90 kilometers from the nearest rural town, and is accessible year round by road.

Population and Culture

In 2003, there were approximately 3000 registered Band members living in the community, according to Indian and Northern Affairs Canada (INAC) data. The population increased by 9.8% from 1996 to 2001 according to Statistics Canada.

Most residents are fluent in English. However, Saulteaux, an Ojibway dialect is also commonly spoken by community members. Although, the community remains predominantly Roman Catholic, many people retain aboriginal spiritual beliefs and practices. Traditional healers live and practice in the community.

Government

The Band Council is comprised of a Chief and Councilors who are elected for two year terms. Councilors are responsible for specific portfolios including health, education, economic development, housing and roads. The Band Council represents the community on several other national, provincial and regional groups including the Tribal Council. In 2003, the Band was assisted by third-party management with financial operations.

Employment

Employment opportunities in the community are limited. In 2003, almost 39% of community residents received social assistance as their sole income. Local employment is mainly available in the public sector (e.g. Band Administration, Social Services, Child and Family Services). The largest employer in the community is the school. Some residents do earn a living through farming, commercial fishing, and small business enterprises (e.g. stores). .

Education

The first school in the community was constructed in the late 1800s. In 1904, a residential school administered by the Roman Catholic Church was built. By the early 1970s, attendance at the school had dropped by 50%. When the Oblate school became a federal day school, the Band declined efforts to send children to a provincial school division and instead negotiated control of its own school. The community currently has two schools servicing students from nursery school through grade 12.

Housing

Most houses in the community are aging and are too small to accommodate inhabitants. Many houses are in disrepair. Several homes have mold problems.

Water Supply

The community gets its water from a lake. Water is treated at a local plant and distributed through the main water line to 69% of homes in the community as well as to community facilities. A truck delivers water to the rest of the homes where it is stored in cisterns or barrels. A few homes have private wells.

4.1B. HEALTH SERVICES

The Health Centre

A health centre, constructed in 1999, forms the hub of health services in the community. The original mandate of the Health Centre was public health but primary care services are also provided by physicians five afternoons a week. Residents also access health services from two community hospitals as well as from major facilities in Winnipeg. Pharmacy services are available weekday afternoons.

The health centre provides health programs in three main service areas: (1) Community Wellness and Education Services (CWES), (2) Community Health and Education Services (CHES), and (3) Home and Community Care.

Chronic Conditions Programs

The Chronic Conditions Programs falls under the CHES team and includes the Aboriginal Diabetes Initiative (formerly the Diabetes Program) and the Adult and Pediatric Chronic Condition program. Adults in the community with known, diagnosed chronic diseases and conditions are identified in a Chronic Condition master register and provided with assessment, health education, counseling and support. Nurses provide home visits for general health assessment including glucose testing, and education. Some screening for blood pressure and blood glucose levels is offered at the health centre.

The Aboriginal Diabetes Initiative (ADI), a component of the Chronic Conditions Program, provides education on the prevention and management of diabetes. A community diabetes worker provides education through workshops, presentations, newsletter articles, pamphlets, videos, and booths at the annual health fair. Diabetes education resources include individual and family counseling services. The diabetes worker maintains the diabetes register and also assists in the coordination of foot care services.

A foot care nurse is available in the community five days every two months. The foot care nurse provides basic foot care including foot inspections, nail and skin care as well as education on self-care. The nurse provides foot care to patients in their homes and occasionally at the health centre.

Medical Transportation Services

At the time of the study, a transportation service, based at the health centre, operated 24 hours per day, seven days a week. Transportation assistance includes both a medical van service, and provision of gas vouchers for clients who wish to use their own vehicles. Transportation services are available to all individuals (with treaty and non-Band status) living on-reserve as well as individuals with treaty status living off-reserve. Exceptions include individuals receiving provincial social assistance who are eligible for federal transportation services (as a lesser priority) in which case FNIHB is reimbursed by the province.

Transportation is provided for medical appointments including physician and traditional healer services both locally and outside the community. Accommodation and meal arrangements are made for clients traveling out of the community. Transportation assistance is automatically provided for medical appointments in surrounding rural towns, [Town 1 and Town 2]. This includes hospital admissions and discharges, weekly doctor and dental visits, as well as prenatal and emergency visits after hours. Approval must be obtained for visits to traditional healers, travel to Winnipeg and other urban centres. Travel coverage for spouses or family members off-reserve is covered only in special cases under compassionate consideration.

Local transportation is typically used for physician and dental visits, visits to traditional healers, prescription and meal deliveries, as well as medical tests including lab tests, Xrays and CT scans. Transportation is provided off-reserve for primary and tertiary care. Services are used after-hours to walk-in clinics, non-urgent visits and emergency visits off-reserve.

Emergency Services

An ambulance service is available. Service is coordinated at a community hospital clinic in [Town 2]. The ambulance service is sometimes used by patients for medical appointments on weekends when the regular medical transportation service is not available. Emergency services include training in emergency first aid and CPR for community members.

Home and Community Care Program

Home care nurses and home care aides are active in the community. Home care nurses provide assessment, planning and treatment services to clients in their homes. Home care nurses assist diabetes patients with preventive care including monitoring of glucose levels and provide education on self-management of feet. Nurses provide post-operative care to amputees including stump care and dressing changes. Nurses also monitor patients receiving home dialysis treatments. Equipment provided to patients for home use includes dressing materials, beds, hoyer lifts, commodes, wheelchairs, and bath aids. A home care equipment maintenance worker is available to check wheelchairs and other equipment regularly.

4.1C. THE STRUCTURE OF FUNDING OF COMMUNITY HEALTH PROGRAMS

FNIHB allocates funding for community health programs according to three types of arrangements: (1) consolidated contribution agreements, (2) contractual services, and (3) transferred health services. Contribution funding for programs is capped and allocated according to Non-Insured Benefits Program guidelines. Contribution contracts are renewed on an annual basis subject to a review of set goals and objectives and strict reporting guidelines. Under such contracts, communities cannot operate programs on a deficit budget or carry over surplus funds. Programs funded by contribution agreements include the Home and Community Care program, the Aboriginal Diabetes Initiative (ADI), HIV/AIDS services, and medical transportation services. Foot care services are primarily provided by a foot nurse on a contractual basis. The services of a foot nurse are funded directly by FNIHB according to a per diem arrangement.

The community began the process of transfer of control of health services in the late 1980s. At this time the community assumed administrative and program responsibility for the delivery of certain health care services previously administered by the First Nations and Indian Health Branch (FNIHB) of Health Canada. Transfer agreements have subsequently been negotiated every five years.

II. RESULTS OF DOCUMENT REVIEW AND CLINICAL SCREENING

4.2 MAGNITUDE OF THE PROBLEM OF DIABETES-RELATED FOOT COMPLICATIONS

4.2A PRESENTATION OF DISEASE

Occurrence of Foot Complications

This First Nation community has some of the highest rates of diabetes and amputation related to diabetes complications in Manitoba. The community is a member of a Tribal Council area with a diabetes treatment prevalence (25%) that is 6 times higher, and a prevalence of diabetes-related amputation (6.2 per thousand) that is sixteen times higher relative to all other Manitobans.

Recorded cases of diabetes and amputation in the community obtained from chronic care and diabetes register documents are summarized in Table 1, Table 2 and Table 3 below. Comparison of cases between years is not valid due to the variable reporting time periods.

Table 1
Registered Cases of Diabetes in the Community

	1990	**1997**	**1999**	**2000**	**2001-2002**	**2002-2003**
Diabetes	94	192	250	248	274	275
New Cases				22	26	15

Table 2
Registered Cases of Amputation in the Community

	1990	1997	2001	2002-2003
Amputations	14	12	7	8
New Cases				2

Table 3
Registered Cases of Diabetes and Diabetes-Related Complications in the Community, 2002-2003

Diabetes	275
Cardiovascular disease	64
Renal failure	15
Amputations	8
Retinopathy	5

Spectrum of Foot Complications

Diabetes and Diabetes Foot Complications Screening

A total of 102 people out of 486 participants in the Diabetes and Diabetes Complications Screening Research Project were identified as having significant diabetes-related foot problems/complications requiring follow-up care. Participants were classified as having significant foot problems/complications if they had signs or symptoms indicative of potential vascular or neurological compromise, and/or soft tissue breakdown. More than half of the screened participants with foot problems were female. The majority of participants with foot problems was not employed and had a low level of education (Table 4).

Table 4
Demographics of Diabetes Complications Screen Participants Requiring Foot Care
N = 102

	n	%
Gender		
Male	45	44
Female	57	56
Employment Status		
Employed	22	22
Unemployed	80	78
Education Level		
0 - Grade 6	41	40
Grade 7-12	39	38
Post-Secondary	21	21

The 102 cases identified in the initial Diabetes Complications Screen were prioritized according to the degree of vascular/neurological foot signs and symptoms in the presence of dysglycemia (FBS ≥ 6.1 mmol/L). Major symptoms included pain, numbness, tingling, and weakness. Minor symptoms included general foot discomfort and temperature changes experienced. Major signs included ulcers, soft tissue breakdown, bony deformity, loss of protective sensation and skin color changes. Minor signs included early soft tissue changes. Priority status provided an estimate of risk of further foot complications and served as an indicator of the need for treatment. Cases were deemed (1) high priority if exhibiting 1 or more major signs with dysglycemia, or 2 or more major signs alone; (2) medium priority if 1 or more major symptoms and/or minor signs with dysglycemia was present; (3) low priority if minor signs and/or symptoms were present. Nearly half of all the candidates with foot problems (46%) had major signs and symptoms, and were classified as high or medium priority (Table 5).

Table 5
Prioritization of Foot Care Candidates

High Priority	Medium Priority	Low Priority	Total
15	32	53	102

Vascular Foot Complications Screening

Among the 102 cases identified as having significant foot problems/complications, all individuals identified as high and medium priority (47 participants) were invited to attend a follow-up screening. The follow-up vascular screen offered a closer look at the foot care candidates with major signs and symptoms. The second screen also allowed the opportunity to further assess vascular foot status and to determine appropriate follow-up care. The screening included a brief questionnaire, foot inspection and Doppler ultrasound ankle pressure testing. A total of 31 out of 102 participants with significant foot problems, 11 with high priority and 20 with medium priority status, attended the second foot screening clinic.

The gender distribution and socioeconomic status of vascular screen participants were similar to that of the larger complications screen sample (Table 6). Vascular screen participants ranged in age from 20 to 69 years.

Table 6
Demographics of Vascular Screen Participants
N = 31

	n	%
Gender		
Male	15	48
Female	16	52
Employment Status*		
Employed	5	16
Unemployed	26	84
Education Level*		
Elementary or less	17	55
Secondary	10	32
Post-Secondary	4	13

* Results from initial Diabetes Complications Screen

Most of the participants with significant foot problems either had a history of diabetes (45%) or were dysglycemic (29%) (Table 7). A high proportion of vascular screen participants had a history of smoking (81%) and continued to smoke (61%). The most common foot complaints reported by patients were pain, numbness and tingling. Other symptoms reported included cramping, swelling, sensations of hot and cold,

Table 7
Diabetes and Foot Status of Vascular Screen Participants
N = 31

	n	%
History		
History of cardiovascular disease	6	19
History of smoking	25	81
Current smokers	19	61
History of foot ulcer	10	32
History of amputation	3	10
Past Foot Treatment		
Never had a foot exam	26	84
Nurse foot care	2	6
Specialist foot care	1	3
Footwear	6	19
Diabetes Status*		
History of diabetes	14	45
Normoglycemic	8	26
Dysglycemic	9	29
Symptoms		
Foot pain	22	76
Numbness/Tingling	15	52
Signs		
Loss of protective sensation*	20	64
Skin problems	18	58
Nail problems	10	32
Foot deformity	5	16
Current foot ulcer	3	10
Doppler ultrasound ABPI test		
Mild claudication	5	16
Incompressible vessels	6	19

* Results from initial Diabetes Complications Screen

discomfort from shoes as well as functional difficulties with walking. A high proportion of participants were found to have skin and nail problems. Skin problems ranged from dry, cracked skin and rashes to pressure points, blisters and scabs. Nail problems included cracked, overgrown and ingrown nails. A significant proportion of individuals reported numbness and tingling (52%), and were found to have lost some light touch sensation in their feet (64%) upon monofilament testing. A foot ulcer was observed in three individuals. Doppler ultrasound ankle pressure testing revealed that at least 5 individuals had signs of mild peripheral arterial disease. Not all tests were conclusive. Several individuals, who had falsely elevated ankle pressures indicating poorly compressible vessels, required further toe pressure tests.

Few priority care participants reported receiving previous foot care. Most individuals (84%) reported never having had a foot exam. Few had seen a health provider for foot treatment. Only one patient with a long-standing foot ulcer was receiving care from a specialist physician. Some individuals (19%) did report receiving custom footwear including orthotics and shoes.

Nearly all participants (81%) in the vascular screen required follow-up foot care (Table 8). Most participants (71%) required basic skin and nail care and monitoring from primary care providers. Many were in need of protective footwear (61%). A few with advanced foot complications required the care of specialist physicians (13%). Fifteen participants (48%) required urgent attention. One participant passed away soon after the screening.

Table 8
Vascular Screen Follow-Up
N = 31

	Referrals	Priority Referrals
Primary Care		
General Physician	5	
Nursing	17	11
Further Doppler Testing	4	
Tertiary Care		
Vascular Surgery	3	3
Infectious Diseases	1	1
Candidates for footwear	19	
Total referrals	48	15
Total participants referred	25	

III. RESULTS OF KEY INFORMANT INTERVIEWS

4.2B PATTERNS OF DISEASE: DESCRIPTIONS OF PROVIDERS

Disease Trends

The enormity of the problem of diabetes in First Nation populations was appreciated by all providers. Physicians and nurses who had worked in the community for many years were alarmed by disease trends. One nurse reported a six-fold increase in the number of registered cases of diabetes in the community over the last twenty years. Providers noted the aggressive nature of the disease in the community as evidenced by the progression of complications:

MD: I've been there [in the community] long enough to watch people go from being quite asymptomatic to renal failure, blindness, um, dialysis, death. I've watched that quite a bit. And, and I feel frustrated because I don't think I'm doing very much for them. . . . I think the progression [in this community] is quicker than elsewhere.

Nurse: The progression, it's either a very, very slow healing process which [can take] up to a year for a small ulcer, or amputations, either above or below the knee.

Physicians reported an increase in the number of diabetes-related complications including cardiovascular disease and renal complications along with the substantial growth in the population in the community over the past two decades. One physician described the change in complication rates:

MD: I remember '87 or '88 when I was in [Town 2], I think I saw the first renal failure or renal insufficiency from, secondary to diabetes. I thought, boy, this is odd. I didn't know, um, Type 2 diabetes could do that. Gee, this is unusual. . . .That was about sixteen years ago. But I, you see it all the time now. So I don't know why it's getting worse so fast. It was unusual then and it's common now. You know, the leaky kidneys and I'm sure the vascular disease goes along with it as well.

A trend toward younger age of onset of diabetes in the community was reported by several providers:

MD: What we see is diabetes in younger and younger populations. That's kind of scary.

MD: And I'm sure many of the kids are insulin resistant and prediabetic. And I didn't see this 20, 25 years ago. Um, 30 years ago as a medical student going up north, I barely saw any of this stuff.

> Nurse: Well initially when I started working here, it was the older groups, you know, the 50s, 60s and 70s. Nowadays we're finding a lot more in the range of say 25 to 35."

Patients in the community typically presented with foot ulcers in their 40s according to one nurse. Earlier onset of complications such as renal problems and blindness in patients had resulted in heavier workloads for health providers according to another nurse.

Providers recognized foot complications related to diabetes as a serious problem in the community. "I think that too many people have something wrong with their foot," one diabetes provider in the community noted. Physicians agreed that a high proportion of patients with foot complications seen were from First Nation communities, and that the majority of cases were diabetes related. The scale of the problem of foot complications was summarized by a physician specialist: "Probably about a third to a half of what we see is from First Nations communities. I mean it's been steady from when I started [about five] years ago. It's been a non-ending, not a stream, a flood. There's been no change. It's a disaster." One resident who had returned to the community after a long absence described the conspicuous change in rates of amputation: "I came back, you know, and I see all these people that I grew up with, with no legs, no hands, uh, some people under, under extreme care, you know. That was a shock to me. . . . People I grew up with. I've known all my life. They're being wheeled around in wheelchairs…."

Physicians recognized the complex pathophysiology of diabetic foot lesions. The relationship between glucose control and the development of foot complications remained unclear for some physicians. Physicians acknowledged that multiple factors were at play in the progression of foot ulcers. Often a minor, isolated event such as wearing new shoes would trigger the process of foot breakdown one physician pointed out. Physicians expressed a tempered optimism for the healing diabetic foot. One general practitioner pointed out that ulcers, even at an advanced stage in high risk patients, could heal under the proper conditions, but also did recur. Specialists asserted that amputation and the progression of foot complications and amputations were "potentially preventable" with aggressive treatment at an early stage.

4.2C PATTERNS OF DISEASE: EXPERIENCES OF PEOPLE WITH FOOT COMPLICATIONS

Initial Symptoms

Confirming the insidious nature of the disease, patients described the early stages of diabetes as quiet and uneventful. Several individuals reported having no symptoms for many years after being diagnosed with diabetes. As nurses and physicians had indicated, people were less inclined to take the disease seriously when they were symptom free. One woman, who began experiencing symptoms ten years after being diagnosed with diabetes, admitted that she did not take her medication regularly until she became very ill. People were often unprepared for the sudden onslaught of severe symptoms that ensued, signaling the onset of complications. One person recalled the first problems he experienced with diabetes:

> Patient: Well living with diabetes isn't what they'd tell me it'd be like. Like I had diabetes since 1980 eh. And then it never started to affect me till 1999 June. That's when I got sick. . . . . Well in '99 what happened was you know like uh in the morning of June, I was very weak and you know I could hardly get up. I could hardly walk. So that's when my friend decided to take me to the hospital. . . . I went to a checkup in [Town 2] hospital, and they told me I had to stay in the hospital. So I stayed in the hospital and then they checked out my uh kidneys. I guess my kidneys kind of uh quit working. So from there on, like you know like uh later on that summer they put a fistula in my arm, and then later on again maybe about 3 weeks later, that's when they send me to uh dialysis.

Confirming provider reports of a disease that was often undetected and easily underestimated in the community, many patients indicated that they had developed progressive symptoms well before they were aware they had diabetes. Contrary to one physician's view that patients lacked an awareness of their bodies, many individuals recalled their earliest symptoms of diabetes in detail. However, people did not always appreciate the significance of these symptoms prior to diagnosis. One individual described how he first learned he had diabetes:

> Patient: How I find that out was like uh, I was passing a lot of urine eh. But I didn't realize why I was passing a lot of urine and I used to drink lot of ah, I used to drink lot of pop and lot of water. Like when I eat like for breakfast I probably drink about a quart of water with juice with it eh. And then I'll have a cup of tea with it. And then through the day like you know like I was kind of thirsty, and I used to drink lots of water. In fact sometimes I'd carry a gallon of water when I used to travel eh. . . . Ah, I went in and got it checked and then, that's when I started having diabetes. I wasn't at the borderline, I was, like it was too late for me to try and do something about it.

Another person recalled having problems with frequent urination for two years before being diagnosed with diabetes. One patient was admitted to hospital for two weeks at the time of diagnosis for symptoms of pain and frequent urination. Two people from the community learned that they had diabetes upon sustaining a heart attack.

Patterns of Foot Complications

People with diabetes described a wide range of foot problems from ankle stiffness, swelling and calluses to foot ulcers and gangrene. Several people reported experiencing chronic, persisting foot pain. Injuries were a common occurrence. Minor injuries sustained by walking or stepping on objects were often underestimated by people and typically resulted in chronic foot lesions. One patient recalled, "one time my feet uh broke open on this side, down here. . . . Well what happened was, I don't know, I must have stepped on something and it didn't heal for 3 months. Didn't heal. I was working that time. Used to walk around, just kept on working. I used to walk on my tiptoes, eh, just keep on going, it doesn't matter how much I get sore, I just keep on working..."

Sensory loss appeared to be a common source of serious injuries among amputees. One individual who had already undergone multiple toe amputations described a recent injury that he was still recovering from: "Just here about a month ago, there was glass on my foot there, on the side of my foot. . . . And they had to cut it again. . . .I didn't even know there was glass there." In another case, one man described how a decision to warm his feet led to serious complications and ultimately to multiple amputations:

> Patient: When I had both legs, my legs are, as I said before, my legs used to get really cold, cold as ice. So I put'em on the feet register there on the floor. And I put a blanket over. They got warm all right. But in the morning, my daughter-in-law happened to come. Said, look at your feet. What? My feet. Oh, she said, they're full of blisters. It's like uh burn blisters. . . . Didn't feel it. Not at all. Had the heat all right but. . . . Ever since then they uh, it helped, um, my legs deteriorated faster [than] ever since the burning. . . . . Took something like 3 months to heal. This one got burnt so bad that toes started turning black. . . . Well they tried to, tried to heal the toes, but they'd heal one toe all right but the other one, the others turned black. . . . And this went on for 2 or 3 weeks. And they found they weren't making any progress cause they were pumping me with antibiotics. . . . After they cut the toes off my foot healed. And I developed a little ulcer or whatever you call it on my ankle, on the left side. It kept... the muscle got weaker and weaker. I couldn't even stand on it. The foot wanted to go sideways. That's what was doing it. They couldn't heal that either, so they cut the leg off.

This man had also begun experiencing numbness and stiffness in his non-amputated leg indicating contralateral progression of foot complications.

Skin and nail problems such as corns, calluses and discolored toenails were common early foot problems reported by amputees. These minor problems coupled with problems of uncontrolled glucose levels, infection or impaired circulation often quickly escalated into major lesions. Rapid deterioration of a chronic foot condition, exacerbated by a series of complications, was a common pattern among amputees.

Many foot problems culminated in multiple, emergent amputations. One patient described the progression of infection after already experiencing bilateral toe amputations: "It started with the foot and came up. It went black about that high and then the doctor told me he's gotta cut it." This person consequently underwent a below knee amputation. Another person reported having a chronic foot ulcer for two years which, upon becoming infected, required partial foot amputation. A more extensive emergency leg amputation followed due to gangrene. This man described the recurrence of gangrene in his other leg, three years later:

> Patient: And then that night, I don't know what happened to my leg. It really got, it got gangrene so I had to have another emergency operation to cut my leg off. And the doctor asked it to me like, "What are we going to do with your leg?" I told him, "Cut it off." . . . It just happened like that. In the morning I get it, and they had to cut off in the same day, like in that same evening they had to cut it off.

Comorbidity

People in the community with foot complications typically experienced multiple health problems. Several people reported a history of cardiovascular and eye problems. One woman described a history of heart attack and episodes of shortness of breath and blackouts. Another patient, who had undergone seven cataract surgeries, reported having temporary loss of vision.

Renal dysfunction was particularly common among patients with serious foot complications. One individual whose mother had renal failure and had passed away from diabetes complications, was apprehensive about his renal status: "Well my kidneys. . . . Sometimes, they don't work. I have to get myself strained out on Sunday. . . . I don't want to take dialysis. . . . I went to the doctor on [Town 1] and I was bloated, like I had too much fluid. And they had to drain me out. . . . I've been in and out [of hospital] for that." Several patients with foot complications had experienced renal failure and were undergoing dialysis treatment. One man reported having only 10% kidney function at the time of his amputation. This person, who had been undergoing dialysis three times per week for four years had adopted a practical perspective: "Well at first I didn't like it. But as time went on I had to learn to accept it, that's all. Nothing I can do about it. I can't quit, can't quit the dialysis." One individual who had experienced multiple amputations described a daily routine of ten hours of dialysis treatment in his home. Sitting in a dining room lined with rows of stacked boxes of dialysis equipment, this patient pointed out that he went through about 78 boxes of supplies per month for his dialysis treatments.

4.2D IMPACT OF DISEASE

Impact of Diabetes

People expressed a deep sense of loss as they reflected on their personal experience with diabetes. For most participants living in the community, diabetes had touched not only their own lives, but also the lives of multiple family members. One man, whose mother and brother had died of renal complications, described his family's experience with diabetes: "Like my uncle, my uncle was only 37 when he had his leg amputated. He's been going to dialysis when he was about 38, 39. He's like 48 already. . . . Well my brother's been really sick of diabetes eh. . . . He has a prostate problem. . . . He had a heart attack when he was about 31, 32. Then he had a bypass." Another resident reported losing three family members – a grandmother and two brothers – to the disease within a span of three years.

Physical disability resulting from advanced complications of diabetes impeded many individuals from living independently. People who had sustained multiple complications described a variety of challenges and obstacles that they faced on a daily basis. "Everybody has their own difficulties out here," one patient pointed out. Several patients reported problems with mobility. One amputee with renal complications described the physical limitations of living with multiple complications with diabetes:

> Patient: They have a bad case of diabetes, they just don't have the energy to take care of their own feet. They feel like doing it but the energy. Like there's a lot of things I like to do. Like in my own case, that's what holds me back. I don't have the energy. I'd like to do it, but the energy just isn't there even though I

> eat accordingly. . . . Well, the only problem of mobility is, uh, some days the dialysis treatment doesn't turn out so good. Feel weak and drawn out so I can't . . . I can't drive the wheels.

Sensory problems often impeded patients from caring for their feet. Some people reported difficulty reaching their feet. One woman with a history of a foot ulcer explained how poor eyesight had affected her ability to care for her feet:

> Patient: It's my eyes, eh. I can't see that good. I gotta wear magnifying glasses to take care of mine because I got ingrown toenails on both of them. So I gotta watch them . . . I just put them in water. I put, what do you call that, vinegar in the water and let it soak for a while and then it's easier. . . . I cut my own toenails. I haven't really come down here [to the health centre]. There's the foot nurse that's down here I guess but I never. Just last week, and it was last week I cut my, I guess I cut things too short. It got real sore. . . . I kind of hurt myself a little bit but I can always put it in the water, eh. . .

A man living in the community who drove for a living had to relinquish his driver's license as a result of eye complications. He indicated that loss of vision was "the worst one" of all problems he had experienced with diabetes.

Impact of Amputation

While a few individuals reported considerable pain relief after amputation, many continued to experience problems. One man noted "I was unable to walk and my legs got so bad they had to amputate one leg, the left leg, and this other one is, I'd say it's about 50% good. It may come off some day in the future. Oh I use it but, still it's uncomfortable." Many amputees never fully regained the ability to walk comfortably. One amputee described how his walking has changed: "Uh, very difficult [after surgery]. I was a person that liked to putter around or do things for someone else. Was an outdoorsman, but now with only one leg, it's not too good either. If it was really 100% I wouldn't mind, I'd be walking like ordinary person, but [it] can only support me for so long so. . . . Still walk regardless." Several amputees who were able to walk, could do so only for short distances limited by other complications including shortness of breath.

For several individuals, amputation was life altering as it had restricted their ability to participate meaningfully in the community. A young man living in the community described how amputation had changed his options: "Oh it's been hard for me. Like uh, I don't do things like I used to do before. Like, like sports. I used to play baseball. Like floor hockey and all those things. . . . All the things I used to do is play ball, go and ride with a bike but . . . Now all I do is go to bingos." One elderly man described the abrupt ending of a life's work with multiple amputations:

> Elder: There's a lot of things I'd like to do, but I can't do that because of uh, of limited...I don't have no legs, and then my fingers are missing and things like that eh. ...I was very active before, yes I always used to work. I was self-employed for 10 years. Umm hmm. That's the biggest thing for me, is you like, you like not working. You know. Cause I've always provided a good living for myself. But ever since I got sick, it's hard and I had to get rid of everything too, you know. Even still now you know like, I could still be maybe able to answer phones or things like that you know. But I cannot do any lifting or any other kind of uh physical work you know. Like I wouldn't even mind myself, I wouldn't mind getting a part-time job, you know. But I could still have some...I still have a lot of good ideas in my head but to put into work. Talking to myself is not going to create any work, you know. It would be nice if I could get a, a part-time job some place you know. Even if I can do like half a day in the afternoon, or things like that you know. It would be good for me if I can get a part-time job, like even in the afternoons. That way like you know, then my wife could work full time, you know. We could both benefit from it.

The challenges of ageing with amputation were described by another elder:

> Elder: See like some diabetic people or elderly people, they can't stay by themselves. Like in my case, I just can't stay alone. I need someone around all the time. Just in case something happens. . . . All of us diabetics are mostly elderly now anyway. We're the elders now. Ha ha. All the really old people are dying off. There's very few left. Maybe there's 3 or 4. And the next generation, like me, take over being old.

4.2E SUMMARY OF THE CONTEXT OF ILLNESS AND DISEASE

The rapid growth rate of diabetes in the community is evidenced by the increased prevalence of diabetes and its complications, and the earlier onset of disease observed in the community over the last two decades. In this population at high risk of diabetes, most providers recognized the problem of foot complications as significant.

The profile of foot complications in the community is reflective of a disease that has been largely unchecked. Providers and people in the community described a wide spectrum of foot complications from early nail problems to late stage ulcers and gangrene. People with foot problems typically experienced multisystem health problems. Renal dysfunction, cardiovascular disease and vision problems were common comorbid conditions reported. Foot lesions were commonly triggered by minor injuries. Minor foot problems, coupled with insults such as infection, impaired circulation and impaired glucose control, escalated into major lesions. Due to the insidious nature of diabetes, many individuals failed to appreciate early, mild symptoms of their disease. People living in the community were commonly diagnosed with diabetes only after experiencing severe complications of the disease, for which they were often unprepared. Amputation was the common result of recurrent infection followed by rapid deterioration of the non-healing foot – an almost incomprehensible series of events according to survivors of the experience.

The human cost of the disease in the community was considerable. People reported the loss of not just one or two, but multiple generations of family members from complications of diabetes. Loss associated with diabetes was a personal and individual experience. Young diabetics noted the void left in their lives by the loss of ability to work. Elders described the loss of independence in the activities of daily life.

The magnitude of the problem of diabetes-related foot complications in the community was perhaps most evident in the experiences of the survivors of amputation. Although some individuals reported considerable pain relief after amputation, most, could not resume activities they had once enjoyed. Some people who had survived multiple amputations exhibited remarkable resilience. These rather pragmatic individuals had accepted their physical disability, but had not given up the hope of regaining meaningful work and self-sufficiency. The inability to participate more actively in the community as full citizens remained the greatest loss for people living with amputations.

4.3 REVIEW OF THE CURRENT HEALTH CARE SYSTEM: KEY INFORMANT DESCRIPTIONS OF THE MANAGEMENT OF DIABETES AND DIABETES FOOT COMPLICATIONS

4.3A. DELIVERY OF DIABETES CARE: THE POSITION OF PROVIDERS

The Personal Practice of Physicians

Casemix

Primary care physicians reported seeing a large volume of patients, who sought care both on a regular and walk-in basis, in the community. Physicians reported "doctor usage" to be much higher in the community than in surrounding rural hospital clinics. Some attributed this to higher morbidity of patients in the community than in surrounding towns. Diabetes and complications of diabetes dominated the practice of general physicians in the community. Diabetes, in concert with hypertension, was reported by physicians to be the primary presenting problem seen among adult patients in the community. Physicians in general practice encountered patients with a wide spectrum of diabetes-related foot problems ranging from calluses and infected toenails to chronic non-healing ulcers and necrotic toes. Patients with burn injuries from heating pads were a common occurrence, physicians noted, despite preventive education efforts. An extreme case of untreated foot injury was described by one physician: "I actually have seen one person with toes with maggots in there. . . .I mean I have seen people that um, even well in Winnipeg actually during my training, you know who broke a plate at home. There was a piece of the plate stuck in the foot and they didn't notice for a whole month, you know till it started to ooze out type of thing. Not healing." This physician also described two recent cases encountered in the community that had resulted in amputation – one patient who had presented with necrotic toes secondary to infection, and another who sustained a third degree burn from a heat register.

All physicians reported seeing patients with foot complications at a late stage, which considerably reduced the efficacy of medical intervention:

> MD Specialist: [I see them] actually at all stages. There's a huge broad spectrum. We primarily see people when everything's fallen apart. But there's some people we see for preventive measures that we initiate interventions to prevent problems. But many times we're seeing people at the end of the line, when there's really certainly nothing that can be done.

> MD Specialist: ...Diabetics have always been, they always tend to come on the later side, you know. I think that's been a problem for years. . . . They come to us late. It's sort of neglected complications. Now, that's where I think the biggest problem is. I mean when they start presenting with problems, you know, by the time we see them, it's too late. You know and I think there, that's the issue.

> MD: You know I always feel I see them too late you know, just maybe uh six months away from dialysis.

Practice of Foot Care

General physicians admitted to performing brief and incomplete diabetes assessments. Glucose testing was occasionally performed. Patients who tested positive on random glucose tests administered by nurses were referred to physicians. Screening of patients for diabetes complications was not routinely performed. General physicians reported that they did not perform regular foot examinations on patients. Physicians were aware of diabetes clinical practice standards but did not believe these standards were practical or affordable to implement in the First Nation community setting. Lack of time and high patient caseloads were common reasons physicians gave for not routinely assessing the feet of diabetic patients. Some physicians indicated that they did not regard foot examination as a priority in their practice in the community. Physicians who acknowledged the importance of assessment in theory admitted, in practice, to performing only selective foot assessments of high risk patients such as diabetics with a history of foot ulcers. Other physicians, who were aware of the risk of missing significant foot problems, maintained a policy of checking feet only if foot problems were a patient's primary complaint.

The practice styles of general physicians varied considerably. Diabetes management styles among general physicians ranged from the conservative to the aggressive. Physicians also demonstrated both focused and holistic approaches to diabetes care. Criteria for clinical decision-making reported by physicians included the nature of foot problems, patient receptiveness to care, patient expectations of care, and age. Perceived low patient expectations and noncompliance of patients to treatment deterred some physicians from following standard practice. One physician reported that prescribing medications was a large part of his practice because he believed that many patients in the community preferred quick treatment of symptoms. This physician also admitted to not providing standard medical treatment to patients who were perceived as noncompliant to regular care, such as patients who were unreceptive to medication or regular testing. A more comprehensive approach was demonstrated by another physician who routinely admitted patients to hospital with advanced foot complications to provide more complete care.

The age of patients influenced the practice of physicians. One physician chose not to treat foot problems aggressively in elderly diabetic patients due to perceived increased risk in this population. This physician rationalized different standards of care for the elderly and the young:

> MD: I guess if somebody's young and they're aggressive and, you know, I want my sugars to be this, this and this, it's a lot easier to say to someone at that age, take, you know, get out walk, here's your, do all the other stuff that you say to everyone, everyone. Anyhow, but you're also adding on other agents and stuff. Somebody's 81, 82 and they're a long standing diabetic and, you know, they're already on a whole raft of medications. Not anywhere near as aggressive with treating those.

This physician indicated that the community setting was not conducive to preventive diabetes care. He believed that aggressive management of risk factors was better implemented in a setting with proper resources for a specialized diabetes program or clinic. In contrast, another physician acknowledged the imminent health needs of the elderly population as a priority in the community: "One doesn't want to forget about the elderly. You know, I mean it will be great if you can prevent it in the younger population, but at the same time you cannot take resources away from the elderly who actually need it right now." The differing approaches to the care of the elderly reveal an underlying debate about the place of primary and secondary diabetes prevention in the community – seen as competing strategies in a system with limited resources.

Specialist physicians favoured a more aggressive approach to foot care relative to most general practitioners. Specialists regarded all Aboriginal patients with diabetes to be a high risk group whose care was a priority. Specialists acknowledged that they limited follow-up care of patients living in remote First Nation communities due to travel constraints for patients. Consequently, specialists strived to provide more timely and accessible care to these patients. For patients in remote communities, some specialists were available for consultation by telemedicine.

General physicians described several limitations to caring for patients with diabetes in the community. Management of diabetes in general was considered by physicians to be especially challenging due to the complex nature of the disease, and the commitment required of both providers and patients. One provider noted that effective management of diabetes necessitated that providers manage multiple systems on a regular basis and that patients commit to a complete lifestyle change. Other challenges described by physicians included the physical limitations of insufficient space and supplies at the community health centre. One physician reported that the clinic space at the community health centre was not well designed for certain medical procedures such as debridements, and could not accommodate sufficient staff. In some cases, effective medical care could not be provided to patients due to lack of proper supplies. Another physician reported difficulty accessing new diabetes medication for patients. Specialists reported difficulty accommodating patients with diabetes complications in a timely manner due to limited operating room space and time in hospitals. According to one surgeon, diabetic cases were difficult to prioritize in relation to other elective surgeries within the current hospital system. This surgeon recommended greater flexibility in surgery schedules to accommodate urgent diabetes cases.

Referral Practice

The referral practice of general physicians varied considerably. Some physicians reported referring patients with foot complications regularly to specialists. One physician reported routinely consulting with infectious disease and vascular specialists regarding urgent cases; this physician preferred to refer patients with foot ulcers at an early stage. Other physicians were less inclined to refer patients for specialist care. One general physician reported referring an average of four to five select patients – primarily patients with signs of ischemia or history of claudication that required pressure testing – to vascular specialists per year. Another physician reported referring only a few, serious cases to vascular specialists, indicating a preference for managing patients with advanced foot complications independently. Aside from occasionally authorizing prescriptions for footwear from nurses, physicians reported minimal consultation with nursing staff about foot care.

The decision to refer was influenced by several factors including the age of patients and patient compliance. One physician was particularly cautious in the referral of elderly patients: "Diabetes, as for the foot problems, well, yeah, probably not as aggressive looking after those either just because they're 81, they've got all their co-morbidities and risk associated with sending them to see a vascular surgeon. The big thing you worry about sending to a vascular surgeon is well maybe they'll operate. Sometimes I don't think it's appropriate to send them." The perception that people would not follow up with specialist appointment also discouraged some physicians from referring patients.

Specialist physicians were open to regular consultation with community providers via telephone or telehealth. Specialists also indicated a willingness to accommodate high priority referrals. Patients who were flagged as urgent or who were referred personally by general physicians, specialists reported, did receive immediate attention.

The Practice of Other Providers According to Physicians

Primary Physician Care According to Specialist Physicians

Specialist physicians were generally critical of the quality of primary diabetes care in First Nation communities. One specialist observed: "Most [patients] aren't on proper medical therapy, you see. And it's a problem because, you know, I don't know why they're not, you know, and if they are on it, it's inadequately controlled. . . . [The pharmacology is] not straightforward but it's, there's a lot that you can do that is not being done, you see." This physician speculated that the problem of inadequate glucose control among Aboriginal patients was due to both patient noncompliance with medication and the prescription of incorrect medication. Specialists were particularly concerned about the lack of primary foot care in communities. Family physicians were not performing foot assessments including complete vascular assessments, specialists observed, because of lack of time due to large patient caseloads.

Referral patterns of primary care physicians described by specialists compounded the problem of patient access to essential foot care. Specialists reported that they were consulted only "occasionally" about patients with diabetes by physicians working in First Nation communities. One specialist reported receiving fewer referrals from physicians working in communities in southern Manitoba than physicians in northern Manitoba. This specialist concluded that physicians in the south were likely not referring patients when indicated. Another specialist suggested that the presence of physicians from the Northern Medical Unit may contribute to higher referral rates in northern communities.

Lack of timely medical management contributed to poor health outcomes among diabetes patients according to specialists. Primary care physicians were initiating foot care and referring patients only after the development of significant complications, according to specialists. One specialist observed that even when primary care physicians identified vascular problems, treatment was often delayed until complications were evident. Specialists reported commonly seeing patients with long-standing foot lesions including gangrenous toes and non-healing ulcers at too late a stage to treat effectively. Specialists indicated that primary care physicians were waiting too long for foot ulcers to heal, and referring such cases too late when options such as bypass surgery were less viable. One specialist estimated that most primary care physicians referred patients after an average of four to six weeks of conservative treatment. Treatment was also delayed when referred patients with urgent conditions were not flagged as priority to expedite care, one physician noted. Specialists conceded that the criteria for referral of patients with foot complications may not be clear to general physicians. One specialist pointed out that decision-making about when to treat a foot ulcer aggressively and when to refer a patient is complex because of the difficulty in predicting the healing potential of an ulcer.

Specialist Physician Care According to General Physicians

Primary care physicians were generally appreciative of the care and support of specialist physicians. General physicians described the care provided by infectious disease and vascular specialists as excellent particularly in the management of urgent cases. Some general physicians noted that access to specialist care could be slow. One general physician reported a one to two month wait period for elective cases to see an infectious disease specialist. Another physician noted that timely access to vascular specialists was limited by a shortage of operating time and beds.

Specialist physicians were somewhat more critical of each other. One surgeon regarded colleagues from other specialties as being too conservative in the treatment of patients with diabetes, and not proactive in referring patients when indicated.

Nursing Care According to Physicians

Physicians generally perceived nurses in the community as effective and adequately trained yet overloaded with responsibility. One physician regarded nurses as the preferred providers of diabetes assessment in a more specialized setting:

MD: There's way more there than I can do so there's lots of stuff that for other people to do. There's lot of stuff for non-physicians to do there which would be just fine. Certainly, serial examinations would be great. Not all of that time. If there was a nurse there interested in or paid to do diabetes, she could. There could be 3 of them there and they could do nothing but diabetes and they can have a great time. There's enough there for, for a specialty clinic.

Nurses were also viewed as playing a valuable role in quality assurance. One specialist recommended that nurses collaborate with general physicians to coordinate priority referrals and medication regimes to maintain basic standards of diabetes care.

Personal Practice of Nurses and Allied Health Providers

Practice of Foot Care

Nurses encountered patients with foot problems of varying degrees of severity:

Nurse: I very seldom see ulcers. And if I do, then that's, I refer them to the doctor or, you know, to the nurse and then it's taken care of that way. Yeah, so most people it's, more or less, it's prevention. . . . Well actually the most, I would say the biggest problem I have is ingrown toenails. Yeah. I would say that would be the biggest, biggest problem. And then there's some people that have problems with circulation but then we kind of refer them to doctors if we have to and then there's a lot of preventative teaching, you know, in their own foot, in their own foot care...

Nurse: [We see foot problems at] different stages. Most of the time with [our] program it's after they've been to the doctor, and sometimes it's a debridement which leaves a big open ulcer. And quite often it's from stepping on glass or a nail and then it has festered. Like they don't have foot care before things happen, it's always after. And then we see them after, after surgery.

With the exception of nurses in the Home and Community Care program who provided regular foot exams and basic foot care to Home Care patients, nurses reported that they provided limited early foot care. One nurse indicated, "...I'm just here to do their nails and I only see them and assess their feet maybe like I said, once every two months." Most nurses reported that they did not routinely assess the feet of diabetes patients. One nurse explained that omission of foot exams was largely a reflection of crisis conditions in which acute medical care remained a priority:

Nurse: I'm guilty of that, I never thought of checking the feet whereas...and in the one case we had here, the person had a problem with one foot and that nurse at that time didn't check the other foot. I happened to see the other foot. And how did this get away on us. So just treating what we were supposed to treat but we should have been checking the other one. . . .Well we don't have any, there's not enough time. And you're so busy dealing with, like the things that are, happen to be crises in that present moment but you don't do the whole thing. You just do what they come in with.

Holistic, preventive care was not accommodated in a system with limited resources according to this nurse:

> Nurse: ...Let's say you've got something, you know, especially an elderly person or somebody that's got a history of different things. Rather than just in and out like a 5 minute and what's the problem. I've been told because I did treatment, don't ask more than what the person comes in for. If you come in for a sore throat it doesn't matter if your foot is rotting off. If it isn't bothering you at that time, leave it. If they come in for a sore throat, you treat the sore throat. . . . We did, up North we were told to be, like we had to be like physicians. I did assessments and treatments too. One of the things I noticed that every time like I said, well how is this, how is that, you'd uncover a whole mess of things. Now, number one, the system probably doesn't have enough resources to cover all of those things that you would get when you start looking at people's health and the multitude of things that are going. So you just sort of address the things that are breaking down at this present moment, that's what you do.

Several factors contributed to the limited provision of basic foot care. Nurses and allied health providers viewed early, basic foot care as a small aspect of preventive diabetes care. One diabetes provider summed up the role of foot care: "...Prevention is the biggest thing. Because foot care alone is just a little part of prevention for diabetes, you know. There's a whole broad spectrum of preventative measures that go into the total care of a person that has diabetes, you know. Foot care is one of them." Patient education had become the main focus of preventive care for many diabetes providers in the community:

> Nurse: Teaching seems to be the real emphasis.
>
> Nurse: ...It's just an ongoing education thing on preventative, you know, treatments, like making sure they, you know, they watch for, what signs and symptoms to watch for complications of circulation and problems with their feet so. And not only that, it's, you know, it's with the whole diabetic teaching thing with diet and exercise. . . . The nurses come by and do the dressings and stuff like that you know so. But, my job, before that, is to just, you know, like is just remind people about the problems with diabetes, what the complications of diabetes [are], the problems that can arise from diabetes. And I just keep telling them that over and over and over again. . . . I always try and stress that it's a very serious situation if you don't get it under control, it can, it's been known to kill a lot of people at a very young age. . . .

Providers disseminated information on disease complications, lifestyle modification and self-care including glucose monitoring and control through workshops and counseling sessions. Providers emphasized individual lifestyle modification particularly that of diet.

The majority of foot care was provided to patients in their homes restricting the number of patients that could be seen. Providers disagreed on the rationale for home-based foot care. One provider explained that home visits were necessary for accessible foot care as a consequence of a change in the health centre's policy on patient transportation:

> Diabetes Provider: ...I usually end up not seeing as many people as I'd like to because it takes a lot longer to drive from one home to the next. But, because of that, I mean you're talking about access, accessibility with clients. Well I uh, if I didn't go out and see them, you know, and do my home visits, I think, I don't think I'd be seeing that many people because they don't taxi them here any more. . . . That actually changed within the first year after I started coming because once I, I got to know where people were living, all of a sudden the clinic came to me, the staff came to me and told me that they didn't have any more taxis available to deliver people to the clinic and back home. So that became a problem for me at first, to kind of. Then I had to say to them well I won't be able to see that many people because I have to go out and drive on my own and that takes a lot longer than people just coming in to the clinic.

However, another provider indicated that transportation was not a limiting factor for clinic-based foot care: "[Staff offer] a lot of home visits for the people that are unable to come here. But I think some of [the people needing foot care] would be glad to get out if they were transported here. And I don't know about medical transportation if they would pick them up, [the transportation coordinator] said yes when I asked her last time.

Patient participation greatly impacted the provision of preventive foot care according to providers:

> Foot Care Provider: ...Sometimes when you go to a reserve because it's a close-knit community, if there's a, there's anything like, um, like a wake going on, even, you won't be getting as many people coming to the clinic, they'll be breaking their appointment. Or if the weather's not that good, you know. . . . It's, a lot of times it's because the people don't come to the clinic. Like I say, there's a lot of people that break their appointments. I could see people, I could see ten people a day if they were here.

> Foot Care Provider: We don't see many of them. I think at the screening there, they see a lot more. . . . People don't necessarily come in, there's too many. I think maybe doctors aren't asking to see the feet when people come in for, if they're diabetic, can I just check your feet. It's something that I don't think they do on a routine basis. We have clinics and stuff like that, like a little health thing. But not every, like, you know, it's usually the people that are the go-getters that are coming but not the people that you'd like to see. And often times the attention gets when there's problems and sometimes the problems have gotten away on the person. Like it started off, they've had it for a while. Never said anything and it got away.

However, one provider noted that the limited provision of foot care services was less a consequence of patient compliance than a result of the shortage of foot care providers: "I think if they can be seen, they'd probably come in to be seen, you know, so it's, it's because there's just not enough people to go around for foot care." Several providers admitted to having limited training in foot care:

> Diabetes Provider: I've more than not really had the foot care training.

> Diabetes Provider: I don't really know too much about foot care...I didn't know what diabetes was. And then when I got this job, I read as much as I could about it. . . . At first I learned it on my own and then I went to that [one week] Diabetes 101 training that FNIHB offers. . . . So I kinda just winged it and then I kind of taught myself how to make, well when I went to college I knew how to make presentations but at the Health Centre here, being new here, I didn't know . . . . I feel like I'm, sometimes I feel like I'm not that knowledgeable about diabetes.

One nurse confirmed that more advanced training in foot care was necessary to better serve the community than the Level 1 certification held by most nurses.

Referral Practice

Consultation with specialist physicians varied among diabetes providers. One diabetes provider reported referring few patients for specialist foot care: "...Not that many because the people that I'm seeing are regular clients so I've maybe referred about three at the most maybe. . . . A lot of times the people that are in the advanced stage, a lot of these people are also going for dialysis. They're in a hospital like every, you know, three times a week so they see the doctors, they see the nurses, you know." This provider typically directed patients with advanced foot complications to primary care physicians or to podiatry and pedorthist services. In contrast, another provider reported regular consultation with specialist physicians:

> Diabetes Provider: We do a lot of referrals [of patients with foot complications], especially out of Winnipeg. And a few doctors that we do work with, work very well with us. Very helpful. And they understand that we're in a remote location, and now we're getting involved in telehealth, so then we can send people to [Town 1] and then they're seen at [Town 1] by a doctor in Winnipeg. So they're really, really working towards continuing care. And they're, they're pretty quick. If we have a referral, then they're very good at getting the clients in right away. . . . [We send a] written referral. We explain what the

site looks like and a little bit of history on the patient. And then they take them in right away. . . . Within the week.

Typical indications for referral of foot care patients, described by one provider, were somewhat more conservative than the earlier recommendations of specialist physicians:

Diabetes Provider: [We refer] any time, any time there's any change. If there's, if, if it's not a dry sore any more. Any foul odors. More discharge. Then we refer. To see if there's something different we should be doing. . . . [We refer cases] when there's discharge, not a clear discharge but odors, then they're referred out and usually for, they end up with debridement. And then they come back home.

Administrative Role

Nurses described a demanding work schedule. One nurse explained that the unique needs of the community necessitated a high level of commitment from health staff:

Nurse: . . . You'll find a lot of people that are, that work here, are involved here, this is a full time job. It's not, you know the health centre might close at 4:30 or so but none of us are ever really that far away from, even in [town 1] I have to get involved with a lot of things. You know people phoning for counseling or help with meal tickets, advice, medical, medical treatment you know, decision making, what to do. It's almost a 24-hour thing.

The clinical work of nurses was affected by the increasing administrative role they had assumed within the heath care system. The extensive reporting requirements by government interfered with diabetes care according to one nurse:

Nurse: I think uh FNIHB and Health Canada are really negligent about services. You know, you hear about uh you know Virginia Wolf and all that. *[The nurse is referring to the Virginia Fontaine Addictions Treatment Centre scandal, where funds were used inappropriately by FNIHB and Band members.]* And then they turn around and they make me spend half of my time doing reports and stuff for them. And there's people out here that are living with diabetes and their blood sugars are 22, 25. *[A normal blood glucose level is between 4 – 6 mmol/L.]* And I haven't got the time to go out and teach them about it or set up workshops because I'm so busy doing all this paperwork. Or else I'm dealing with the treatment aspect.

Navigating a highly bureaucratized health care system had become an integral part of nursing care in the community. One nurse described the elaborate process of securing medical supplies for the community:

Nurse: Basically it ends up, the person that's offering the service will get in touch with me, or the client itself will be advised. For example, physiotherapy in St. Boniface hospital in Winnipeg wants to get special gloves and special stuff for this fellow, this new amputee who is on peritoneal dialysis. And they don't have a clue what to do. And so they will, if they are lucky and the person is coherent that they are dealing with, they will refer them to me and I will fill them in on the requirements. For example, for physiotherapy if she wants a wheelchair for somebody, she writes up a referral, sends it to me. I fill out the 230 form and if necessary, I get the doctor to take a look at it. We've got a 'signature doctor', he's here

> today. And, and he'll sign anything for me, even my release papers probably [laugh]. But we have a rapport and, and I usually will get the doctor to sign the prescription, get the necessary write-up, and then there's your 230 forms or your special medical treatment form that Medical Services or FNIHB needs. And you send all this stuff in, you know, and hope and pray they don't lose it. I photocopy everything and put it on their files because, if you don't and like I do so much paperwork, if you don't, I'm screwed. . . . Fortunately, we have a pharmacist here that, he's been coming up as long as I have pretty near. And he knows the ins and outs and we work really well together. And he's able to get a lot of, a lot of stuff, from homecare equipment stuff right through to you know medication stuff that's not on the FNIHB list. Yeah, well it saves a lot of time because we did have a spell there where they changed this whole routine and it was, it was a real paper trail just to get stuff.

Nurses also mediated the provision of foot care services for patients by facilitating physician referrals for footwear or foot care, or by directly referring patients to podiatry services.

Values

Veteran nurses in the community had acquired a deep appreciation of the living conditions of residents. Some had incorporated this understanding in their practice. One nurse recognized that conditions of suffering in the community necessitated a more humane response:

> Nurse: . . . Interestingly enough, it was an Aboriginal person was told by an Aboriginal person who had more training than the other one actually said, 'Well, you know, you can't get that close to people, you know, like you have to maintain this professional setting and you can't really get too involved with people.' And I talked with that nurse and I said, 'But you did. It's ok.' Because if that's, if that means for that person, those people, that they know with an assurance that in spite of the miserable conditions that they live in which is, they do live in miserable conditions. They have very little resources.

This 'contextual understanding' of the community precipitated a shift in this nurse's expectations of patients and providers. Advocacy for patients became a central value of practice for this nurse:

> Nurse: I scaled down my expectations that if some, we can make somebody, like this is in the school setting and it's also here, if in some way we can make somebody's life a little bit more, uh, like that has some sort of quality to it that they know that, that somebody cares about them that, that we've accomplished something. And that's sort of like taking the worst case scenario and is making as much as you can on the only things that are not, don't cost any money. And that's caring. Caring doesn't cost, money-wise. And that's the only thing that we can actually do. . . . If all we can do is to help maintain a little bit of, like the dignity. Help with the medical condition in whatever way we can. Advocate for that person because they cannot advocate for themselves and show that we honest to goodness care that this person was here on this earth. And that, you know, we're actually like, we're actually fortunate to, to meet some of these people.

Nurses held differing views on the role of conventional medicine in the community. An Aboriginal nurse directed community members toward more conventional medicine:

Nurse: … A lot of people, especially Aboriginal people, will go into traditional healing and they'll want to go and see a medicine doctor. And I mean that is a choice, that is their choice. But I often try to, when they talk to me about traditional healing, I also try and say, well, you know, conventional medicine is also there for a reason. Like you can use your traditional ways but conventional ways are also there for a reason, you know, they can work together to bring out the best in your health status, you know, so.

Conversely, a non-Aboriginal nurse acknowledged the value of integrating the traditional beliefs of the community into medical practice:

Nurse: I'm very open, in fact that's one of the very important things about the nursing position is to be aware of the cultural beliefs and, and, and the medicine, and I have taken a lot of time and patience to, to find out and be aware. And now, I've gotten to an openness where I will, I will just sit down and just ask them, um. Yeah I get some of them that laugh at me, you know they say, "Puh, medicine man, that's voodoo." But there are. . . . Well there's, there's a variety of outlooks. There, you know there are some families here that, that, 'Medicine man, you gotta be crazy.' And then there's others that are very agreeable.

Despite advocating an inclusive health care approach, this nurse viewed the culture of the community as deficient:

Nurse: It's a whole different ball game here. This culture just doesn't, doesn't run efficiently like, and as unfeelingly as, as I find like, and that's one of the reasons I fit in so well, is, is I, I've kind of shed that, that lets do this, you know, and instead, you, you work with them, and you know you learn as much as you can about their culture, and… you go at it their way. Instead of the way the doctors and the provincial health and the federal health people want. And uh, you last a lot longer here, as a nurse and there's probably less chance of a burnout.

The Practice of Other Providers According to Nurses and Administrators

Standards of Physician Care

Nurses were generally critical of primary care provided by physicians and described it as substandard. The practice of symptom management did not effectively meet the needs of patients, one nurse observed:

Nurse: I'd like to see doctors that were a lot more conscientious of the people, and that would give them the care according to the guidelines that are set out. Be a lot more conscientious about the kind of care they give instead of just sort of here's a pill, try this. 'Uh your blood sugars are too high, we'll put you on insulin, and I want to see you in a couple of weeks, so's we can taper off the insulin and get you on.' That's not teaching them anything. They're not learning.

Lack of timely patient referral, reported also by specialist physicians, was confirmed by nurses. Nurses indicated that primary care physicians either delayed or chose not to refer patients with foot complications to specialists: "They do [refer] when they need the surgery. Or when that looks like it's getting to a point of no return. But not beforehand that I know of."

Corroborating reports by physicians, nurses indicated that the quality of primary care in the community was directly influenced by type of physician payment. General physicians who were reimbursed on a fee-for-service system did not meet recommended standards of diabetes care, according to health administrators. Nurses and administrators described the impact of variable payment systems on primary care in the community:

> Nurse: . . . The doctors in this area, they know about it, but they really don't follow the guidelines that the diabetes, much the same as they do as they do with the sexually transmitted infections. You get people running around here without VDRLs done when they should be. But the doctors don't follow very closely. And, and it's true, because they're so damn busy. Trying to meet, uh, keep their finances going because they get, the one set in [Group 1] get paid for the number of people they're seeing. And that works really great in the fact that the people get in and out real quick, for medications and stuff, but they don't sit down and spend that time, that time due for helping with counseling or doing the checks and, um, it recently came to light that virtually nobody checks feet, and it should be done. And I'm just as guilty as any of the, of them as well. But I know better. And then there's the doctors in [Group 2] and they're paid um by the hour. So they have a flat rate. And that drives these folks nuts too because they're so used to the other doctors, you know kinda pushing them in and out real quick. And these guys sit down and they do work with the person, and that means that the waiting time for the other people is phenomenal. And you have a mixture of people coming in for treatment and um also for diabetes problems and all. A whole myriad of things that all end up waiting an hour in the hallway. So that doesn't work terribly well either. It does work a little bit better, in the fact that those that want that kind of attention do get it.
>
> Administrator: If there's more people coming down to see the [Group 1] doctors, it works for us but also we're worried because there's no quality services, because they're not being seen properly and diagnosed. . . . The same [patients are] coming back over and over again and when we do the deliveries, like those little bags you see you know right away what's in there. And there's a lot of abuse with T3's, things like that. And that kind of concerned us.

Standards of Nursing and Allied Health Care

Nurses and health administrators were both critical and complementary of the care provided by allied health providers in the community. One non-Aboriginal nurse spoke favourably about the commitment of allied health providers from the community: I would have no qualms about [a person in the community] taking care of feet. She's a very thorough and very meticulous lady. A lot of the people that do that take on those responsibilities are very conscientious and meticulous people that just don't do it for the profit. You'll find that a lot of people here that do acquire the training, they're in it for the community.

One nurse linked gaps in diabetes care to inadequate training of lay health providers:

> Nurse: We got the community diabetes worker in, and we did focus a lot more, but there's not as much being done as I would want, or I feel should be done for the man hours. . . . I find that I'm the only person that's working on the, with diabetes in a professional role. Now that we do have a community diabetes worker in, there has been a lot more to show for it as far as support groups and one-on-one education and stuff. But due to their knowledge base and uh, they're, they're more or less just lay persons from the community. They've had some training, for example, [a local] College will provide uh community diabetes worker training, and that will definitely get them but they can't do things like check people's blood sugars or do any of the hands on stuff with confidence. They can try and do it. They do what training they do get from [the College], which is good, because it does give them a sort of foundation or grounding, but there needs to be a lot more done."

Some diabetes providers had little or no clinical training. In fact, with the exception of the community foot care nurse and two home care nurses with advanced training in wound care, one administrator admitted that few professional providers in the community had specialized training in foot care. One nurse observed, "There are not very many that are providing foot care services that I'm aware of. There are a few, for example, [there] is one lady that I've known that's taken the foot care training, and yes she will provide you know service, but it uh usually it's on her good will or else it's the person will pay her themselves." Consequently, few health practitioners were able to provide foot care in the community.

Lack of capacity in diabetes care was associated with several factors. The work environment for health providers did not promote high standards of care. One nurse reported that unfair hiring practices favoured the employment of family members of health centre staff, thereby impeding retention of qualified staff. An administrator explained the social implications of correcting these practices:

> Nurse: When you tell somebody here they're not doing their job and they're, like the repercussions are pretty bad because then you know that you're taking, probably taking away that person's livelihood. Well you are. And they're going to end up on social assistance. Plus, I mean there's a certain sense of family too. There's a family loyalty. There's a lot of that professional stuff doesn't really come into play 100%, because people have a tendency here to favour family. You know like if your family, your family unit, that means your uncles and your aunts and all that kind of stuff, and you've got a job, it's not uncommon if you've got a job that you're also helping out a lot of those members. If you lose your job, a lot of those people go.

Professional development opportunities and supports for health providers in the community were limited. While administrators indicated that staff training opportunities at the health centre were growing, diabetes providers indicated that little support or mentorship was available from more experienced staff at the health centre.

Providers also traced the problem of professional development of Aboriginal health providers to the social environment of the community. An Aboriginal administrator observed that Aboriginal staff who had acquired experience outside the community appeared to function at a higher level than staff who had remained within the community:

> Administrator: ...It was a work ethic before like, if you want anything, you have to work. That was sort of the standard out there. So you can almost see that there's almost like this whole way of belief system the way the world, like how you operate in the world out of here. And here, it's completely different. The people sometimes, if they've been there, they get maybe their education but there's some kind of, sometimes they sink into that same kind of fear here. And others they're, they live here, they've gone here and they maybe lived a bit there, they come. When they come back, they bring with them a lot of those, that other, those good things, not the bad things hopefully the good things that come from the outside in. And you can really tell who's been educated out, who are the self starters, the go-getters. . . . What I think is the most important, the most important thing a person has, is their willingness to go an extra mile if they have to. Their curiosity or their self challenges. Like challenge yourself. . . . Interesting enough, the ones that have those qualities are people that have had some off reserve experience. And either living off the reserve or working off the reserve. They've done that at some part of their life, even schooling off the reserve, they've been schooled off the reserve for some segment of their life. . . . They grow up different, in a different world and they grow up with there's, there is a white man's world. There is this thing where you can't depend on anybody else, you have to depend on yourself. You don't have this kind, not necessarily have that ethnic support system if you want or in the milieu anyway. . .

The support system within the community was, this administrator determined, paradoxically detrimental to its residents as it had fostered a loss of independence and loss of confidence that was reflected in the work of health staff. The lack of adequately trained health providers in the community was ultimately seen as a reflection of the community's tolerance for dysfunction:

> Nurse: In some situations I know people get away with things that I think they would never get away with in the outside world. It would never be tolerated. And, and it shouldn't be tolerated. But we do tolerate it here, you know. . . . Because I think that, I think it's just, you know, that there's a certain dysfunctional, dysfunctional. We're dysfunctional, you know, I mean we behave dysfunctionally.

The Practice of Amputation

Physicians offered diverse personal perspectives of amputation. One primary care physician expressed an appreciation of the loss and disability associated with amputation: "You know amputation to me is kind of the last resort. So if the foot can be saved, you know because the disability with not having one leg is enormous, I mean even if you lose one toe, you lose your balance and you have trouble walking. " This physician believed that even in high risk cases where amputation was often inevitable, delay of amputation was prudent. Conversely, another general physician described the benefits of amputation: "Surprisingly, after they do get an amputation, they improve. A lot of things seem to improve, heart failure, diabetes control."

Specialist physicians regarded amputation as an unfavourable outcome. One specialist addressed common misperceptions of amputation:

> MD Specialist: The patient may have a perception that the amputation was done too quickly. What the patient doesn't appreciate, is that in the decision-making process, there is years of experience. No one wants to take off a limb unnecessarily because then that patient is basically housebound or bedridden. . . .We're dealing with two board certified foot and ankle surgeons and two infectious disease physicians who have a specific interest in this area, and two vascular surgeons who are very well trained and don't want or need to do any more than they have to do.

Specialists regarded amputation as a consequence of both late presentation of patients to specialists and poor control of risk factors, implying missed opportunity on the part of both providers and patients: "I think you should be seeing less amputation. The reason that we're amputating is because they're getting to us too late. That's number one, and number two there's risk factors. Patient compliance, medication...."

Health care providers offered a more pragmatic rationalization of amputation when considered within the context of the health care system. Nurses acknowledged that amputation had become a common option for treatment of foot complications. One nurse indicated that for many patients presenting with advanced foot complications amputation was inevitable:

> Nurse: Oh they just get to the point where the pain is so bad they go to the doctor. The doctor looks at it. If it doesn't look like it can be, you know, adequately treated because it's too far gone, they'll amputate. If it looks like, you know, like they'll do maybe a x-ray so they can see what kind of, like what's the circulatory system like in that leg and let's say if it it's simple. And if it looks like it's so compromised, you know you've got all of this circulation that's collateral circulation only that's supplying your leg, well let's just amputate.

Providers described a heath care system accepting of amputation as a feasible option and consequently more tolerant of foot complications. In a system driven by cost effectiveness, amputation presented a practical and convenient solution to the management of foot complications one nurse observed:

> Nurse: . . . Amputations are fast. It's a lot quicker to do an amputation than it is to have somebody in the hospital over a period of time trying to cure a diabetic wound. They're long. And it probably is much more costly in the long run if you take a look at the whole thing. . . . Amputating, amputating is expensive stuff but if you take a look at the person through transportation, if you added up all those things and the frequent hospitals and the necessary. Like you added up everything that person would have to have in the course of that treatment in order to get the thing healed up, my guess is that there's got to be awfully high. You're looking at maybe hospitalization, you're looking at cost of medication, you're looking at, you're going back for debridement. . . . Amputations are expensive too but they're, once you get the person's amputated, it's like that, they're done. They go home quickly. They go for rehab and then they go home too. And then there's like there's a high cost to that too, prosthetics and stuff like that. Chances are here they would, there are some people that have prosthetics but a lot of them don't use them.

The option of amputation had diminished the significance of foot complications as a serious problem within the health system, one physician reflected: "Diabetes foot complications are a significant problem, but they are one of many problems related to diabetes. Perhaps more sinister than foot complications is kidney failure. The foot complication's easy. The patient has the amputation, the problem is gone. Dialysis, on the other hand, is a problem that goes on for years and years and years."

The decision to amputate was characterized as complex and multidimensional by specialist physicians. In some cases, as one physician explained, amputation served as a humane option:

> MD: Many times disease comes to us in the stage that we could spend a lot of time fiddling around with dressings and antibiotics but, in fact, sometimes, depending upon the nature of the lesion, it is most efficient to proceed to an amputation with a good fitting prosthesis. I mean, we could hold that person hostage for years fiddling around with something that is non-salvageable. If, I mean, the patients are given the options, right from the time that we see them. If that's not satisfactory, then we'll do whatever their wishes are, knowing that in some cases it's a futile endeavour.

In many cases, however, the decision to amputate was not clear according to one specialist: "A limb-threatening infection is a case for amputation. Pain and non-revascularized disease is an indication for amputation. And the rest of it is all grey. There's a lot of, a lot of palliation that we can do with antibiotics and just pressure relief." Hence, specialists placed amputation at the extreme end of a continuum of foot care strategies. One surgeon described the context within which amputation is considered:

> MD: If someone has to travel to Winnipeg once a week or once every other week plus endless dressings, being confined to a wheelchair and having a malodorous limb, I mean, you have to weigh that...plus the risk of overwhelming infection, versus an aggressive amputation early on, whether physically stable, and a good fitting prosthesis. So all of these issues, I mean it's not a simple decision. Oh, you know, you've got a sore on your foot and the leg comes off. And that's foolishness because there are many things we can do to try and heal that. But, you know, it gets to the point that sometimes you've done all the measures possible, and ultimately the lesion comes to us in a non-salvageable state...So whenever we see someone, we weigh the risks and the benefits of a conservative approach, which can be something as simple as, you know, watch your diet, stop smoking and get your wife to pare the callus, to something as aggressive as, you're coming to hospital, you're getting intravenous antibiotics, you're going to have your little toe cut off because it's infected. And then we're going to put you in a cast afterwards to protect the foot. So there's a whole broad spectrum, depending upon how the disease presents.

4.3B DIABETES CARE: THE POSITION OF PEOPLE WITH FOOT COMPLICATIONS

Provider Understandings of Roles

Participation in Primary Care

Patient contact with the primary health care system was of particular concern to physicians. One specialist compared the health care system to a factory: "…It's an assembly line. It doesn't matter what point you enter the conveyor belt, you will see all of the assembly line workers as you get on the conveyor belt. The problem is you have to get on the conveyor belt." General physicians observed that patients in the community did not always visit physicians in the community regularly, nor did they always see the same physicians. Patients who visited multiple physicians were discouraged from doing so in order to maintain continuity of care according to a nurse: ". . .Generally they will get a doctor. There are some people that doctor hop. But they get, generally get found out. And the doctors are getting pretty stiff about if they come in and they want to you know to start on insulin or back on pills, he'll say, 'Well I'm sorry you know, I'm not the regular doctor you're going to have see' " . One physician noted that although patients reported having one regular provider, they often sought care from several different sites. According to nurses, residents with serious foot problems often sought additional care in clinics or emergency departments of surrounding community hospitals. One administrator observed that early hospital discharges had resulted in an increased number of outpatient visits to rural hospitals for dressing changes. Reports by administrators of an increased number of visits to traditional healers indicated that patients were also seeking care outside the mainstream medical system.

Lack of continuity of care was linked by some physicians to poor health outcomes in the community. One physician suggested that physician continuity of care may explain some of the variation in foot complication rates between rural and urban communities:

> People living in the cities are actually much more aware or tend to go to a physician you know on a regular basis, or more often. I think here [in this community], especially with the elderly population, they are not used to visiting a doctor on a monthly basis. And they say, 'Well this is not too bad, I'll just wait for awhile, don't want to bother you.' You know so on. And so they end up showing later just because they didn't think it was so serious.

Providers agreed that people in the community typically did not seek foot care "early enough". Providers speculated on why people with diabetes did not seek early or regular primary care. Some physicians suggested that patients lacked initiative both in seeking care and in self-management of diabetes. People who were proactive in self-care were perceived by physicians to have better outcomes. Physicians also suggested that people who lacked formal education or who were non-English speaking were less likely to see a physician regularly. One diabetes provider suggested that people with higher levels of education were more likely to seek alternative foot care options: "I hate to say it but the ones that are working, I guess, or educated get foot care off the reserve. But the ones that that are not very well educated kind of just stay home and wait." One physician noted that many First Nation people believed that doctors should only be seen during serious illness and often would wait to see if a health problem resolved with time. Another physician suggested that First Nation people with diabetes were often asymptomatic because they had adapted to a state of hyperglycemia, and because they lacked both an awareness of their bodies and an understanding of the disease process – characteristics this physician associated with the culture of the community. Alternately, other providers suggested that as a result of the insidious nature of diabetes, the disease was often undetected or underestimated:

> Physician: ...We are aware that there are a lot of people with diabetes that have not been diagnosed and don't know it. And I guess it comes insidiously .

> Diabetes Provider: Again I think [people think] it's not going to happen to them. You know, they have the diabetes, they're aware of it. Or some don't, they're not aware that they have the diabetes. They don't come to the screening. And then they find out afterwards.

Providers recognized that many residents were simply preoccupied with more pressing concerns than their health such as food and housing. Finally, providers acknowledged that limited access to family physicians both inside and outside the community impeded patients from receiving regular primary care.

Providers identified compliance with medical care as a significant issue among patients who did access primary care. One physician suggested that patient noncompliance with medications contributed to poor control of blood glucose levels. Physicians speculated that some patients were unreceptive to prescribed medications because: (1) they did not wish to add to an existing heavy regime of medications, (2) they were afraid of becoming too dependent on medication, or (3) they preferred alternative therapies. Supporting these ideas, one nurse added:

> Nurse: There's a lot of people that, even though they do know, they've been given all this information, there's a lot of them that aren't compliant, you know, so. . . . There's a lot of people that just, some people just won't take their medication neither because they think it makes the diabetes worse for some reason or other, you know. And then a lot of people, especially Aboriginal people, will go into traditional healing and they'll want to go and see a medicine doctor.

One specialist concluded that both individual and systemic factors contributed to the cycle of poor primary care in communities:

> MD Specialist: There's no consistency for direct delivery of primary care. Someone's there for two years, someone's there one year. . . .and sadly much of the primary care that is delivered in many First Nations community, is management of disasters. There's no proactive intervention because the patients don't show up for the routine visits. They just show up when there's a problem. It goes back to the patient. If the patient doesn't see the family practitioner, the nurse clinician, doesn't keep their appointments, what do you expect? If the community doesn't support the patient, what do you expect? I mean the Health Sciences Centre, St. Boniface Hospital have the doors open 24 hours a day...

Participation in Preventive Care

Participation of community residents in formal preventive care efforts was generally low according to providers. Diabetes education services in the community, including workshops, counseling sessions and clinics, attracted only a small sector of the same community residents, nurses noted. The community fitness centre attracted few people with diabetes. Young people in the community were the primary users of the fitness centre. Few youth, however, participated in diabetes services unless they experienced serious problems. Lack of transportation and telephones were barriers for many residents according to one nurse. An Aboriginal nurse suggested that personal health held little intrinsic value for residents: "Yeah [people in the community] don't want to do anything without any incentive eh? [They say], 'Like we've got to get paid or you know, like what am I going to get if I attend?'.

Patients who were referred to diabetes education services outside the community often did not complete the programs. One nurse suggested that language and cultural differences were deterrents to accessing services outside the community:

> Nurse: Because there's such a cultural difference. . . . A lot of the information is you know, you don't have a high education level here. Um, and you have extensive use of Saulteaux. I'm finding that the English usage is a lot more now, you know as the population ages there's less and less and lot better English representation. But a lot of people don't want to go, not much support systems you know. For a male diabetic, we try and send down the partner who does the cooking and stuff. You got to figure those pieces into the equation too.

Several nurses indicated that cultural understanding was essential for providing effective care in the community. Aboriginal status and the ability to speak the local language served as an advantage. One Aboriginal nurse noted: "I don't know if it's because I speak Ojibway so they might feel more comfortable that way." Trust was identified as another key factor affecting patient participation in health services:

Nurse: . . It's slow when somebody starts. Like for me, as an example, when I started nobody knew me. They didn't trust me. And they'd go to somebody they were, and now, I'm just flooded with people coming in because they all know that. Number one, I'm there, and number two, I know what the hell I'm doing. And how to do the services quick, reasonably quickly and efficiently, and also to get around the system in some areas as well.

Participation in Tertiary Care

Patients made few visits to specialists using the medical transportation service according to one administrator:

Administrator: We don't have many specialist trips. Visits to specialists are mostly to pediatricians, optometrists and orthodontists. Visits to diabetes specialists are rare. Mostly they would be to surgeons for amputations. . . . With the Home and Community Care program in place, they've been doing a lot of the dressing changes. But what we found from that program is that there is a lot of follow-up with specialists. And because [home care nurses are] catching a lot of these other problems, they're really good following and making sure that the doctor is aware of what's happening with the clients.. . . . There are not many referrals to kidney specialists, but there have been an increase in visits to heart specialists. . . . And we also noticed that over the years we rarely had any dressing changes or counseling trips off reserve, but we're seeing a lot of that now.

Several providers identified patient compliance with specialist appointments as a problem. Primary care physicians and nurses reported that patients referred for specialist care did not follow up with appointments. One primary care physician estimated that patients in the community did not attend 25% to 30% of scheduled specialist appointments, and that many did not follow up with scheduled medical investigations or tests. In some cases, patients who missed appointments exploited health services: "Abuse of the system does happen. We've had cases where we will rush a client to emergency, and the client then disappears. Abuse also happens with personal vehicle use. We'll confirm a medical appointment and issue a gas voucher. Then the client will cancel the appointment and keep the voucher. This happens mostly in family groups."

Providers offered several reasons why patients missed tertiary care appointments. An Aboriginal nurse associated noncompliance with the culture of the community:

Nurse: There's a lot of people that [miss foot care appointments]. . . . Well sometimes it's cheque day. Sometimes, and there's family allowance day, then there's end of the month when they get their pension cheques, they'll miss appointments and stuff like that. Going shopping and stuff there. And I find that, I mean I'm not, and I'm not saying this to be, you know, rude, but some people just don't call. They won't call, they don't have that kind of responsibility where they say I'm sorry, I won't be able to make it today, you know, they won't do that. But it's, I found generally that it's not just foot care they do that with, it's just a whole bunch. It's even specialists, they, they complain the specialist here is shitty and stuff but I hear that in the city too, if they break their appointments, they have to pay for their next appointment. . . . Well personally I think like because I'm Aboriginal myself and I've worked in quite a few Aboriginal communities and I come from an Aboriginal community myself, I think that a lot of times people aren't very structured with time. I think is one thing. And it's something that people just kind of have to teach themselves is to be, you know, to have this structured time. Oh yeah, I have to go and do this at such and such a time. It's not part of their... it hasn't been part of their life, you know, but in some cases it is, but in a lot of people it isn't neither, you know, so. . . . I think that it's like some people don't really get up at such, at a certain time, you know, some people are so structured that they get up at certain, but with a lot of native people it's not like that you know. And I find that, I don't know what it is about keeping appointments, but a lot of it, like I said before, it's a hard time for them in terms to keep appointments.

One physician observed that elderly patients were unable to attend appointments due to lack of availability of family. Long wait times discouraged others from keeping appointments. Transportation was identified by providers as a common reason for missed appointments:

MD: No taxis, transportation, forgot, they don't have the time. I don't know how they, you know they don't go to work, like the days don't seem quite the same as for you and me. ...Maybe if it's a mum, you know kid got sick. Pick the priority, and there's a lot of things. And, I guess you know they maybe decided that they don't want to do it and don't want to do all that. Some other family member needed their help more, so it just, you know that may happen.

Nurse: ...Transportation is a hard thing for them. There's a lot of people that don't have vehicles. So unless they get family members to come and pick'em up to take them there, you know, wherever, they just might not want to, to interfere and, you know, ask them to come and take them somewhere, whatever. I think that transportation is a big thing too here.

The socioeconomic status of patients also played a role in whether patients saw a specialist according to one administrator: "I find that clients who are educated, who are professionals or employed will ask doctors questions and tend to see specialists more. Those who are uneducated will simply follow doctors' orders."

Contradicting some of the provider reports above, specialist physicians reported a high patient attendance rate. In fact, specialist physicians and administrators described patients as proactive in seeking specialist care:

MD Specialist: I don't have that high no show rate, unless it's weather related. But as a rule though, obviously you get no shows, but I mean not high. . . .It may well be 1 in 10. 1 in 10 Aboriginal patients. You know what, maybe even less than that. I don't find that the absenteeism is that bad. In fact, what we

> usually end up having is people just show up because they know that we're there. So they just come. . . .I mean, even, I have lots of patients who call me directly.

> Administrator: A lot of them do [keep appointments with family physicians and specialists]. [People in the community] do make their own appointments. They notify us that okay we have an appointment at this time. They either request a medical van or they're going to be using their own vehicle like. And we take a lot of time confirming and verifying these appointments.

People's Experience with Diabetes Care

People's Experiences with Primary Care

Few people with diabetes reported receiving early care. Most people admitted that they usually visited general physicians only after developing specific problems. One amputee admitted that he had stopped seeing his physician regularly several years after being diagnosed with diabetes because he did not believe it was necessary. Another person reported, "Just when I get sick, then I'll go. I'm not going to go and see a doctor just for nothing, unless I have difficulties or something like that." One man, with a four year history of calluses prior to his amputation, would visit his physician periodically when his foot became problematic: "I went to see [my doctor] every time it was red."

Many patients had been prescribed medication. However, contrary to the impressions of some physicians, these patients were dissatisfied with their medical care. One patient explained why he had stopped seeing his general physician: "Cause my doctor's been using me as a guinea pig. . . . Like he just gives us, like if there's something wrong with you he just gives you like any kind of pills like. And yet when you read it in the book and those aren't the right pills he's giving you." Other patients reported not taking prescribed medication either because they felt they had too much medication to take or because they had simply forgotten to take their pills.

People with diabetes spent considerable time in hospital. Most people in the community reported having frequent hospital admissions for foot complications, cardiovascular problems and renal problems. Patients were typically admitted to hospital by their general physicians for periods of time varying from two weeks to two months. One patient was hospitalized for two months to control blood glucose levels. Prior to having bypass surgery and eventually an amputation, another patient reported having six hospital admissions for recurrent foot infections.

Most people with foot complications reported receiving some education on foot care including general hygiene, nail care and callus care from both nurses and physicians. People with renal complications also received instruction on nutrition and diet modification. People were aware of diabetes education resources offered in the community, but few participated in them. The nature of some education services discouraged some individuals from taking part. One amputee pointed out that most diabetes workshops primarily targeted people without diabetes, excluding those with diabetes and complications of diabetes.

Patients offered varied impressions of health care providers and the diabetes care they received. Some people spoke favorably about physicians in the community. One patient commented, "[My doctor] is a nice person." Another noted, "She's a woman doctor. She's more understanding." Some patients expressed confidence in their physicians during times of serious illness. One woman noted, "[The doctors], they help me out. If I'm getting real sick, they know right away what's going on with me." People in the community were most appreciative of the care received from nurses: "Oh they're pretty well thorough in every aspect, you know, they're there to treat you as best as they can. Make us comfortable as possible." Some had developed greater trust and confidence in the care of nurses than physicians: "I get a lot of information from [the nurse]. I'd rather see him than the doctor. . . . Cause, he knows what he's talking about. . . . A lot of people see [the nurse] for their diabetes."

Some patients were critical of the care of general physicians. One patient questioned the expertise of physicians in the community: "[Doctors outside the community] know better over there anyway, instead of going to [the doctors in Town 1]." Confirming the reports of provider, patients noted that the care received from physicians in the community was inconsistent and influenced by fee structures. One young man was particularly critical of the quality of care received from fee-for-service physicians in Group 1.

> Patient: They should get more, proper care from doctors. . . . Because some people they don't, they just go see a doctor and they're in and out, but not like [the doctors from Group 2] who'll keep you there for about half an hour. . . . And some doctors, they just look at you like you're a spare tire and they send you out right away. . . . Yeah, it could get better, yeah.. but if the doctors listen to a patient, but they don't listen to the patients. . . . I think the doctors are seeing too many patients at the Centre per day. . . . More money I guess. Because [the doctor from Group 2] is getting paid by the hour and [the doctor from [Group 1] by the patient. There's 60 people there, they don't see them for half an hour, for 60 people.

Self-Care Practice

People living in the community with diabetes were not passive in the management of their feet, contrary to the views of many providers. Many people chose to care for their feet independently using a variety of regimens. One person treated long standing calluses by soaking his feet in warm water and soap. Several amputees had adopted a daily routine of washing and moisturizing feet. Patients with advanced foot lesions also practiced independent basic foot care. One person tried soaking her foot in vinegar and water upon initially developing an open wound. Another person, whose sister had successfully treated a foot ulcer using herbs described how she had managed her own foot ulcer: "I took care of my feet myself. Used to put it in water all the time. Salt water. And when I go to sleep I used to put a plastic, something like that plastic around my feet, eh, and in the morning it was so clean." Some people who opted to care for their own feet simply underestimated the seriousness of their foot problems. One amputee described initial attempts to manage an infected foot: "Well I took my nail off here. . . . I took it off with my fingers. . . . Started getting red and black. I didn't go to doctor. . . . I thought I could heal it myself but I didn't."

People in the community were motivated to care for themselves for a variety of reasons. Self-sufficiency was highly valued among in the community, and a key reason why many individuals chose to manage foot problems independently of health care professionals. Taking care of oneself was a source of pride for some. One resident associated foot care with values of cleanliness and self-sufficiency: "I've always been clean, my family, my grandma, my mom and everything. We always had a clean place. Always look after ourselves. It's important to look after, that's the most important thing, [for a] person to look after themselves." Residents were accustomed to being self-reliant. One individual who had been managing chronic foot pain independently, with occasional visits to a nurse, remarked, "I've been on my own since I was fifteen and I've been taking care of myself since then. . . . I mind my own business. I'm just trying to take care of myself ." People who were self-reliant with foot care were characteristically averse to depending on others. One woman recalled that her sister had refused early foot care and delayed treatment until she required an amputation because she "didn't like depending on people." Another suggested that people with foot complications relied too heavily on physicians for foot care: "I don't think they take care of themselves cause lot of people having their legs like amputated left and right. . . . I think they're too busy depending on someone; they're depending on their doctors."

Many people with diabetes in the community took care of themselves believing they had few other choices. One individual, who had experienced multiple amputations as well as renal complications, regarded self-monitoring and adherence to a strict diet and treatment regimen as vital. This person was extremely conscientious about controlling blood glucose levels and maintaining his own personal medical records. Another individual with multiple complications of diabetes explained why she managed her own feet: "I do it myself because I have to. Nobody's gonna take care of me. So I keep telling those other diabetes, the ones that got diabetes, you have to do it yourself. You have to take care of yourself. Nobody's gonna do that for you I tell them, eh." People who cared for themselves typically had low expectations of professional care. One amputee indicated "Well there's nothing really that can help me further like, all I do is get the cream and apply cream on my legs and feet, keep them soft. If I don't, they get dried and caked, like the skin of a snake or something. I don't think anybody can do any more."

4.3C THE HEALTH CARE SYSTEM

Organization of Care

Coordination of Care

Diabetes services in the community were not centralized within one program. Rather, diabetes care was delivered via several different programs. Tensions were apparent between staff from different programs limiting collaboration between diabetes providers. One nurse noted, "We have to work fairly closely together, and I don't, like I used to do all these fancy dressing changes and stuff until Home and Community Care started up and their staff kind of pushed me out of that. So you see they're kind of pushing me out of all these little areas." The organization of patient medical records in the community also limited collaboration between disciplines and timely access to information according to physicians. One physician described the management of medical records: "There's not an efficient way to get lab results back to [the community] and get charted into the charts in [the community]. And there's two sets of charts. Physician charts and community and mental or public health nurses have charts which are independent. So, well it's hard to run any kind of a primary clinic out of the [community] health centre." A nurse described the communication process within the existing system of charting:

> Nurse: What we've been doing is, if we do a foot assessment or even like with the wound care for instance, we have our own charting system in the home care program. If we know that client's going to be seeing a doctor that's coming from [Town 2], we write them a referral with a copy of that thing directly to them or we send it directly to the facility and make sure that the doctor gets it prior to their visit. Like we don't put it into the chart that's there unless it's something that we need them to see, or like it's a problem or if you notice something that's irregular.

Communication between providers was limited. Most providers in the community worked independently of each other. Staff who were employed on a contractual basis were particularly disconnected from other health providers:

> Diabetes Provider: Well, I feel that I pretty well work on my own here. . . . I have never seen the physicians here. Because they come in the afternoon and most times I'm gone doing my foot care visits. . . . Sometimes I'd like it to be a little bit more, like as far as communication wise, I'd like to communicate more with the other people that are working here but because I'm gone in the community so much, I'm only here for, sometimes I'll only come for two people here in the morning, then I'm gone. I don't see anybody for the rest of the day. . . . I haven't had an evaluation since I've started working here. I'm not, but I'm not really their employee but still, I still come here to provide services and I think I would appreciate, you know, an evaluation.

Many physicians were unaware of what diabetes resources were available in the community. Some general physicians were unaware of the presence or role of the foot nurse in the community. Other providers were uncertain of the availability of the foot nurse. One provider noted, "I don't even know when [the foot nurse is] going to be here, if she's going to be here this month or not. So there's a lot of lack of communication." Some physicians were aware of diabetes education services offered in the community, but were uncertain how to refer patients to these programs. Physicians also indicated that they were not kept informed of community events including the Diabetes Complications Screening Study.

The flow of referrals in the community offered a glimpse into patterns of communication and the organization of foot care in the community. Referrals for basic foot care and diabetes education were usually initiated by nurses in the Chronic Care and Home and Community Care programs. Community members who participated in education workshops as well as in the Diabetes Complications Screening Study were also referred for foot care. In most cases, referrals were not acted upon resulting in a growing wait list for foot care. One foot care provider claimed to have been uninformed by health centre staff of foot care candidates identified through community diabetes screening. Providers shed more light on the lack action on foot care referrals as they explained the process of coordinating foot care in the community:

> Diabetes Provider: Referrals for basic foot care come from Home and Community Care. Sometimes the doctors will send me a referral, or people just come in asking for help. I'll direct them to [the diabetes worker]. She should then fax the referrals to [the foot care nurse] ideally. It's unclear whether she [the diabetes worker] knows this or not. But the foot care nurse's clinics are now full, so the only way new patients can get in to see her is if someone on her caseload dies.
>
> Diabetes Provider: Well I've had a lot of problems because I have no control over the foot care schedule and there is, and when people are referred to me from Home and Community Care or if they phone themselves and they want foot care, I don't really have anything to do with the appointments. . . . Like when they talk to me about foot care, they make it sound like I'm the one who can get them the appointment and I can't. I just have to put them on a waiting list.

Scheduling of patients referred for basic foot care was managed independently by providers resulting in a closed process. The process of triaging of patients with foot complications was not based primarily on patient medical status as one provider revealed:

> Diabetes Provider: Well usually what I do is, it's the people that have been regular clients. I always, I always say that these are a priority. People that have seen me and people that are there when I go to see them. Those people are a priority to me because they have kept up their appointments so I would say they are a priority. And I go by that. . . . So what I usually do is I have my list of people that I'm seeing and if I have, I'll usually write a list of back, like back-up people. If I miss someone from before, they're a priority to me because they're already my regular clients but there's spaces where if there's a space, I'll see someone new usually.

This provider, who maintained a relatively static caseload of patients, admitted that new patients referred for foot care could not always be accommodated:

> Diabetes Provider: ...The people that I have now, I've been seeing for actually three years now. . . . I'll try and fit [new patients] in. I'll try and fit them in if someone has cancelled. I have a list..., I'll put their names down. Like I have a list of names that, who can be seen, and I do get referrals from the screening, the foot screening. They'll often give me a referral list. If I feel that these people need to be seen, if I have the time, I'll see them. If I don't well. . . . If someone's passed away, then, you know, I take that person off my list and then just say well there's room for this person in here if I need to see someone else. . . . But since this last year, and I've told [staff at the health centre] that I can only see so many people."

Consequently, few new patients were able to access existing foot care services in the community.

In contrast, access to weekend foot care in community hospitals for patients in the Home and Community Care program was well coordinated and streamlined. One nurse described the close collaboration with hospital physicians:

> Nurse: ...Because we're only open Monday to Friday, we have a close working relationship with the physicians because then they're followed up Saturday and Sundays. . . . I think it works fairly well. We have, we can update the hospital on a Friday to what's coming in for the weekend. And then we have an updated progress report usually from one of the physicians on. So it goes back and forth. So if there's any other recommendations, or sometimes we make recommendations on maybe a different dressing that we could use or try, and the doctors work fairly close with us.

Priorities

Physicians admitted that much of the primary care in the community consisted of acute care and short term management of crises. Community residents were typically directed outside the community to the hospital system for chronic care and urgent care. One specialist noted that primary foot care in First Nation communities remained focused on the management of symptoms of foot problems rather than systemic factors such as lack of appropriate podiatry care. Prescription of medication for acute problems comprised a large aspect of the care provided in the community. One physician was critical of the system for fast-tracking patients. Prioritization of acute problems was a response to a high demand for care under crisis conditions according to providers. One nurse described the impact of crisis conditions on the delivery of chronic care:

> Nurse: As far as our chronic adult program. It needs a lot more attention. I find through the years, it's not changed much, just jumped from one flame to one fire to another. And yeah I'll get started on work plans for, for people and boom all of a sudden it's, it's work plan, like I'm talking about care plans and stuff for people. And then boom all of a sudden, now we've got to have all these reports done, and we have to go through the work plan and revise it, and drop everything, you know. It doesn't matter how many STDs are running around out there infecting the community, and we're in there doing all this planning and stuff, and then we'll go hard at it for maybe a week or 2 weeks and then, it's something else has come up. Say a new proposal comes for something else, and they're pulling staff into that. It's just hopscotch. That's all it is, I, it's really frustrating that way.

Such work conditions also limited collaboration between providers in the community, according to one physician:

> MD: People work very independent of each other. There's not a, [nurses in the community] have their job, and they'll call you if somebody needs to be assessed, or a home visit, things like that or else you know somebody's sick at home and they have high sugars, but there's not an ongoing discussion regarding diabetes management between team, because the physicians that are going up there right now, they're not up there just to do a diabetic clinic or such. They're doing ongoing care of people that follow, plus a walk-in basis, plus whatever else happens to comes through the door. So it's not like you have specific time allotted for such, and it's always very, very busy up there. So you do not have a lot of time to sit around and chit chat with somebody about just uh, which might be somewhat helpful but it's realistically it's not, the time's not there. . . . Well, our interactions with each other probably are at the crisis, crisis point. And do we talk about the regular run-of-the-mill stuff? No.

The acute care system had an unexpected impact on patient behaviour. Some patients, aware that the system prioritized acute cases, feigned symptoms such as chest pain in order to receive more immediate attention one physician reported.

Preventive care occupied a smaller place within the community's health care system. Although considered a priority by most providers, routine diabetes screening was not available in the community. A past screening project described by one nurse was an indication of the capacity of the existing health care system to accommodate screened cases:

> Nurse: We had a peripheral vascular disease clinic come in many, many years back. And it was... you know it was good in the sense that, yeah, we found quite a few people with compromised circulation. But you know what do you do with them? We didn't, we provided the service and yeah, we sent them in to see the specialist maybe a couple of times and he told them to quit smoking and that's about it. . . . You know the follow-up leaves a lot to be desired or the continuity.

The education of patients about diabetes remained the focus of diabetes prevention strategies in the community. Providers expressed mixed views about diabetes education efforts in the community. Some believed that diabetes education had had a positive impact on the community:

> Diabetes Provider: . . . I think that overall, there has been an improvement as far as awareness goes and prevention, you know. People are doing more. They're, they're aware of the diet, they're aware of the exercise, they're aware of all the do's and don'ts and most diabetics are now because of all the, I think there's a lot of educational material that's out there now too, that they get, so they have access to that. And I know that a lot of clinics are focusing on diabetes prevention and just teaching, you know. . .

> Diabetes Provider: People are getting more educated and they're starting to watch their own diet. . . .They're becoming more educated in diabetes and they're realizing that we can't take care of them but it's up to them to take care of themselves and that's why they're coming forward and asking for the foot care.

Acceptance of individual responsibility for managing health was viewed as a measure of successful education according to the latter provider. Other providers were less satisfied with diabetes education efforts. Physicians perceived education services in the community to be both unorganized and ineffective. One nurse questioned both the efficacy and the ethics of health promotion strategies that failed to address systemic barriers patients in the community were facing:

> Nurse: How do you tell somebody to be proactive when all they can do is just get through their day? I mean, like I think there has to be a bit of realism. I don't think, I think, if they're going to do anything, if they're going to make a difference on some of those issues, then they have to have some sort of strategy to help address the systemic difficulty. . . . You get angry at people. You tell people you got to take care of yourself. You do that. And you advocate for health act.., healthy living styles and all this kind of stuff. But, you know, it's kind of mean because I can go into a home and I can advocate for health, better styles. In that home there's overcrowding. People have no personal space. Um. Housing is poor. Uh...What is, like what am I asking them? Am I asking them something that's impossible. I have to ask them, I have to try to promote that because that's my job. But am I asking them something that they actually have the ability to do. And I think that we don't have, in a way, they're not empowered to do it themselves. And why? What hope is there? So you take good care of yourself. For what? To live in a hell hole. You take good care of yourself to live in a hell hole. This is a third world area in Canada. Third world.

Availability and Access to Care

Availability and Access to Primary Care

Lack of adequate human resources in the community was identified as a problem by most providers. Physicians acknowledged that current nursing staff loads were not sufficient to provide adequate diabetes care in the community: "[One nurse] looks after most of the patients, and there are over 300 people with diabetes. I mean [this nurse] has no time to check on all of them. I don't think that's reasonable. I think there needs to be more people there." Patients also recognized the need for more nursing care:

> Patient: We need more funding in order to have uh adequate services you know. . . . More funding, and more workers, more nurses.

> Patient: Weekends, sickness doesn't stop, right. You keep on being sick on the weekends and to need people that time. That's what I told the nurse before, like on the weekend, you're not going to get a break from being sick, you're going to be, kept on being sick. . . . Somebody should work in the, be on duty on the weekend.

Physician availability was equally problematic. With a few exceptions, most physicians did not work in the community on a long-term basis. Lack of continuity of primary care was reported by physicians to be a common problem in many First Nation communities. Physicians admitted that although they were available five afternoons per week in the community, patients could have difficulty accessing primary care in the community on a regular basis.

Patterns of physician visits by patients indicated that access to regular primary care in the community was indeed challenging. One woman reported no longer having a regular physician since her physician left the community. Many patients visited at least two general physicians on a regular basis, usually in hospital clinics outside the community. Patients occasionally visited different physicians at different sites. One amputee reported seeing one general physician for regular visits in [Town 1], and occasionally saw another general physician in [Town 2] for gastrointestinal problems. One physician suggested that patients perceived care in community hospitals as more stable and consistent. In fact, easy access motivated most patients to see physicians in community hospitals. One patient reported that he chose to see physicians outside the community because they were available more often in rural hospital clinics. Another patient described the difficulty of seeing a physician in the community "... I was sick in November. But I had to go back to the doctor in [Town 2]. Go and see him there because I couldn't. It's always busy here [at the community health centre] all the time. When there's a doctor, it's just packed in here all the time." Access to general physicians both inside and outside the community had become increasingly difficult for community residents, according to an administrator: "We don't have a majority of people that are going to Winnipeg now because there's been some kind of real conflict at [Town 1] hospital, or in the clinic, where you have to wait sometimes as long as six weeks before you can see your family physician." According to this administrator, increased wait times to see rural physicians had led to a corresponding decrease in visits for specialist care, as well as an increased demand for after hours care in walk-in clinics outside the community.

Availability and Access to Foot Care

Most participants recognized that existing foot care services did not adequately meet the needs of the community:

Diabetes Provider :...There should be more people available to provide foot care.

Diabetes Provider: ...Some people want to be seen once a month but [can only be seen] every two months. . . . I think there's probably more people that need to be seen in the community because this is a huge, like 4,000 people in this community, and I think their elder population is probably fairly high, you know...

Diabetes Provider: [The foot nurse] comes in five times every two months. So three days one month, two days the next month. Her caseload has just mushroomed. And with the diabetes screening project that was here, the list just went up, you know it's up over a hundred I believe.

Administrator: In those two days a month, that [foot nurse] doesn't even hit the tip of the iceberg, let alone. . . .
Like it doesn't hit the needs. . . . Two days a month. . . . That's the foot care program.

Diabetes Provider: I find that we could use [foot care] many more days than what [is] allotted. I think [it is] two days a month and we have many, many more clients, than what [can be covered] in those two days.

Patient: We should have like someone here [to provide foot care], like 5 days a week like working hours just like nurses. But there's nothing like that in the community.

One provider defended the current system of foot care delivery citing improved foot health outcomes:

Diabetes Provider: ...For the amount of time that [we] have, I think [foot care services are] fairly good. . . . It's been good. I was talking to [an administrator who] was telling me that since they've had foot care in the clinic that amputations have dropped and, you know, complications of diabetes. People seem to be aware of the complications that they never knew before so I think that's a bonus, you know. . . .I don't think [foot complications and amputations are] as bad as it used to be, from what I understand. I don't think, because of all the, like I said, there's access to the, there's referrals being made all the time if they need to be. The clinic is here. There's nurses that go out into the community and I don't think it's as bad as it used to be but it could be better. Yeah, I think it could be a lot better.

In fact, both provider and patient accounts revealed that few people in the community received basic foot care. One provider estimated that approximately forty community residents received basic foot care on a regular basis. A few patients reported receiving occasional nail care from nurses and physicians prior to developing foot complications and having an amputation. However, most patients, even those who sought regular primary care, reported that they had not had their feet checked prior to developing foot complications. Patients typically did not receive regular foot exams or general diabetes assessments until after having an amputation, or as part of dialysis care. One individual with bilateral leg amputations who received diabetes assessments as part of regular renal care indicated, "Never got my feet checked till it was too late."

Few people in the community could access early, basic foot care. Select groups such as individuals attending diabetes education sessions and patients in the Home and Community Care program were more likely to receive foot care services according to one provider. Most patients, however, were unable to obtain an appointment for foot care. Many community residents were uncertain of when they could access care, as foot care providers were not available at consistent times. One patient with chronic foot pain and calluses described his repeated attempts to obtain foot care:

> Patient: I tried to see the, tried to see someone for my feet. Tried to go out to the foot clinics. But it's always full. When someone comes out to it, it's always full. . . . Cause mostly the people that see that [foot care nurse] that comes out here, is the staff. . . . She only comes once a month or once every 2 months. And the people that see that foot care nurse is the staff, like the health centre staff. . . . I'm still waiting. . . . Every time there's a poster on the wall, and then I come in and they tell me it's full. . . . She only sees like 10 patients at a time.

Some individuals with foot problems had simply stopped seeking care. One patient who had decided to manage her foot ulcer independently noted, "There's supposed to be [a foot care nurse] here but they haven't come and got me or. . . . I bet they're all busy, eh." Providers also experienced difficulty in arranging foot care for patients:

> Diabetes Provider: You can't get anybody get in there. You can't squeeze anybody in to foot care. And then there's no place to send'em. It's just like they have to just go home and wait and some of these people since I, have been waiting since I started here. . . . And if an opportunity ever arises, like if there's a vacancy or an opening in the foot care schedule, then I, then I try and squeeze one in but it's usually a battle. . . There was a guy that just had his foot amputated and I was trying to get him to get to foot care. He was, and he never did have any [care]. I think now they're amputating his other leg. And I do go visit the ones, like there was three or four on that list that really needed foot care and I haven't been able to get any of them to get any type of treatment. And it's really bad.

The extent of the community's foot care needs was not fully appreciated by all providers. Prior to the implementation of the Diabetes Complications Screening Study, diabetes providers seemed unaware of the demand for foot care:

> Diabetes Provider: . . .I didn't know that foot care was really high needs until I went to that meeting for the diabetes screening. But I kind of figured it was, because I had lots of people on my list.

> Diabetes Provider: We don't have like a really long, long waiting list of people to see me so I think. . . There's probably about 4 or 5 people that have wanted to be seen.

The community health administration underestimated the need for foot care. This became more evident in 2001, when medical transportation services for foot care at the health centre were discontinued. This decision was based on the health administration's designation of foot care as a lesser priority relative to other health services in the community, one administrator explained:

> Administrator: ...At the time with the foot care, it was decided that the demand wasn't that high, and because the funding was coming from somewhere else, they'll be doing the home visits where we don't have to pick up [foot care patients]. . . . That's where a lot of confusion occurred as well is because since we only have six [vans], when we did have eight before. They figured okay, we wouldn't be able to handle it, so okay, we won't, we won't use that service [for foot care] for the time being.

Local transportation services for foot care were eventually restored in 2005, when administrators acknowledged foot care as a high priority.

One provider estimated the wait for foot care in the community in 2003:

> Diabetes Provider: Last time [I checked] there was about 120 people on the waiting list. It's been this high since about, um, probably it's been high for a long time. . . . [People waiting on the list] don't get any type of treatment. Only if somebody passes away and then there's an opening in the foot care schedule. . . . They come in and they ask me how far am I on the waiting list? And I say, same place you were last time.

This static wait list was likely an underestimate of the actual number of people requiring foot care as many residents had admittedly stopped seeking care. The wait for foot care, one nurse noted, was especially risky for patients with diabetes: "They wait. [Some patients receive treatment] about every second month and that's, that's a long time, especially for the diabetics. And there's some that have ingrown toenails and then they run into problems so." One administrator, critical of the lack of initiative of diabetes providers in addressing the actual demand for foot care, summarized the attitude of providers: "This is all I get, so this is all I do. Even if [the foot care provider] knows the need is there."

Access to Footwear

Appropriate footwear proved to be elusive for most community residents with diabetes-related foot complications. Several patients expressed dissatisfaction with their shoes due to discomfort or poor fit [006, 009]. One patient observed, "I seen a lot of people come in here hardly walking. Some of them can't fit their boots, they can't fit their shoes [009]." Physicians raised concerns about the reliability of assessment of diabetics for footwear. One physician questioned the quality of podiatry care that patients received:

> MD: I think it's actually really frustrating from the point of view, is that I know I had also a gentleman who got shoes from a dealer who is actually supposed to be certified. You know whatever. Ended up having an ulcer because of that. Sent him back twice to have it redone, and at the end I think they finally somehow adjusted it, but I don't know whether he went through another ulcer or not? . . . .Then I think they refused him for another pair because he got the one pair like within a two year period.

Another physician noted the challenges of assessing the diabetic foot: "Once people start to have neuropathy, getting assessed for proper footwear and insoles is difficult [016]."

People in the community typically had to incur the high costs of prescribed footwear due to limited coverage available. One individual who had undergone amputation received coverage for bilateral shoe modification, but had to pay for the shoes post-amputation. Another amputee pointed out that his shoes were no longer subsidized due to changes in footwear policy: "They used to give me special made shoes but they couldn't, they quit that. . . . Was 5 or 6 years ago. . . . They used to pay for them. Now I gotta pay for them."

People eligible for subsidized footwear experienced wait periods ranging from a few months to a year. One person who had been waiting two months for an appointment for "special shoes" observed, "There's lots of people that are waiting for special shoes." A woman with a foot ulcer remarked, "They said they were going to give me special shoes but they never did." Travel distances complicated the lengthy process of obtaining custom footwear according to one nurse:

> Nurse: We have some [people] with amputated toes, so they need the special fittings and that's not done here. It's usually Winnipeg or Brandon so it's quite a distance. . . . I think the coordination goes very well. But it can be three to four trips for fittings and then that's, and sometimes then you end up with people who, you know, have different plans so they cancel and we can be looking up to a year. And then you can end up in the meantime then with different foot problems because they're offloading.

Contrary to this statement, an administrator described a case in which access to shoes had been delayed by poor coordination of care:

> Administrator: …There was this client that had an ulcer at the bottom of his foot due to their shoes, the kind of shoes that they were wearing. So I had contact with his doctor and his doctor said, oh yeah, we did a referral already. And you have to wait till his ulcer heals before he can get fitted for shoes. So then, six months down the road after the ulcer was healed, he had to go back for another referral by the doctor because by then the prescription was no good for that thing. So then he had to wait to go see his doctor to get another referral. Then by the time he got a referral to go back to the specialist, which is another three or four months down the road because they can't just fit you in wherever. They have a long waiting list. And then by the time he seen that guy and then went and got fitted for shoes, it was going to take another month before he gets his shoes. So he has to go for a second fitting. By then he had another ulcer. So he started all over again from scratch. You know what I mean?

Access to Tertiary Care

Many people with foot complications revealed that they had not received treatment from specialist physicians. Several patients had been treated exclusively by their general physicians for foot complications including foot ulcers. One person, who had already undergone a partial foot amputation, was denied referral for specialist care upon developing toe complications despite repeated requests to see his former surgeon: "I went to and made another appointment to see [my doctor]. They told me to wait for another month. Because everything was hurting. . . . There was a sharp pain in [the toe]. . . . A lot of pain, yeah. Couldn't put it down this way. . . . I told [my doctor] to make me an appointment to see [the specialist], but he wouldn't do it. . . . He say just wait, and told me to wait until it falls off". This patient consequently had a toe amputation and continued post-operative care with a different general physician at a different clinic.

A few people reported that they had been referred to vascular and infectious disease specialists by general physicians. In fact, patients reported that were usually referred for specialist care when foot problems had progressed to an advanced stage, corroborating reports of late referral by both specialists and nurses.

Patients were generally pleased with the care of specialist physicians. One person described the foot care received from specialists in Winnipeg as superior in comparison to foot care in [Town 1] hospital. Patients referred for specialist care did not experience significant wait periods. One patient who was referred to infectious diseases for a foot ulcer received immediate treatment including debridement and casting of his foot. People were willing to travel routinely outside the community for specialist foot care. A patient who received regular wound care outside the community after an amputation noted: "I went there for six weeks. Back and forth every morning. . . . I didn't mind going back and forth because I wanted to get a, I wanted to get where I was, get everything all squared up." Another woman who no longer had a regular general physician continued to follow up regularly with a vascular surgeon for calf and leg pain. A few patients with multiple health problems found traveling to visit specialists outside the community to be time consuming, costly and fatiguing. One individual who had sustained bilateral leg amputations described the experience of traveling outside the community three times a week for dialysis treatments:

> Patient : There were tough times I had, [when], I traveled from here. We'd leave here at uh 5:30 in the morning. And then we'd get to the hospital before 8:00. And then I had complications. And then I never used to come out of there till about 10:00, 11:30 at night eh. . . . By the time I come home, yeah. And then I have to go back again the next day eh. We start out 5:00 in the morning, you know I spent time more time like you know, like I was more tired from traveling than seeing the doctor or being treated.

Transportation

The community's medical transportation service was regarded by nurses as one of the few efficient programs in the community. The transportation service had been instrumental in facilitating access to traditional medicine, according to one nurse: "Transportation has improved a lot over the years. . . . We have staffing in there, that are very responsible and they've got excellent policies and procedures in place. They share a lot of information with me and keep me up to speed so that I know what's happening. . . . They allow people to go and see their medicine man." Regardless, transportation was identified by community residents as one of the most common barriers to accessing medical care. Many residents in the community did not own a vehicle. Some patients did not own a telephone and had difficulty arranging transportation for medical appointments. Not all residents used the medical transportation service available in the community. Several residents indicated that they preferred not to use transportation service because the taxi service was usually late or involved long wait periods. One resident preferred the independence of traveling by bus to appointments outside the community. Family members, though not always available, served as the main source of transportation to the community health centre for many people.

The medical transportation service was not fully accessible to all individuals in the community. Administrators admitted medical vans were not equipped to accommodate clients who required assistance with transfers or who used wheel chairs. Consequently, clients with special needs such as those who had sustained amputations or strokes were transported to medical appointments either by stretcher handivan from [Town 16] upon special approval, or in some cases by ambulance. One amputee revealed the challenges he experienced traveling to medical appointments:

> Patient: they're unable to transport me because of uh they don't have no wheelchair access van eh. . . . when I was told to come from the hospital...they couldn't provide me transportation, cause they didn't have the right transportation. I haven't been to the clinic for a long time. Cause I don't have no wheelchair van access to go, or a wheelchair car access. . . . There's another guy here that doesn't have no legs eh. He also needs to have wheelchair transportation to go to Health Sciences Centre or St. Boniface. Like I think last time he went, they had to take him by a stretcher service, you know.

This patient suggested that wheelchair accessible transportation would be beneficial for the whole community: "I think it's time that we get our own, our own wheelchair van instead of uh depending on somebody else. Not only that, but it would also create a job for somebody you know. Maybe one or two people. Could create a job and make a living out of it." Plans were underway to install medichair lifts in vans and to use ramps for clients with wheelchairs, according to one administrator. However, past attempts by administrators to secure additional funding from local and federal governments for a handivan with an automatic lift system as well as for staff transfer training had been unsuccessful.

4.3D BEST PRACTICE: PROVIDER RECOMMENDATIONS FOR MANAGING DIABETES AND DIABETES FOOT COMPLICATIONS

The Role of Preventive Care

The place and value of primary and secondary diabetes prevention strategies in the community was debated among providers. Physicians generally supported primary prevention strategies as a greater priority than secondary diabetes prevention initiatives based on effectiveness of interventions, cost and patient receptiveness. One physician reflected: "Access to care for prevention is critical. Access to care after there's a problem is too late. I mean it's critical to have that care but it's too late. You need the first piece which is preventing the initial problem." Prevention efforts were considered by some physicians to be too late to effect change in the elderly, or in people who already had foot complications. Other providers recognized the importance of investment in secondary diabetes prevention strategies for the community. One nurse reflected:

Nurse: If they ever wanted to make a dint in the problem, they would have to take a look at those other things I talked about, which would be a lot of early intervention programs and screening programs and

> automatic assessments on every person that comes in for diabetes. Especially in a population of an at-risk population like we have high diabetes here. It's known. Chances of people having diabetes is very high. So then just make it as a part of the routine to do that by physicians and nurses. . . . And it would be nice if we had a good old, like a foot care, a foot care clinic. . . . And early detection and intervention to see if you can actually prevent something from breaking down to such a degree where the person. And it's money thing. If they invested more that way, you know, with hospital costs and transportation costs, you know, all that kind of stuff, they would probably lessen the costs on the other side of it. But to get there, you need to invest in that first part.

Screening of all First Nation people with diabetes for complications was supported by some nurses and physicians. A nurse pointed out the advantages that early diagnosis offered:

> Nurse: I'd like to see everybody be tested. Then they can become aware if they do have diabetes. And then that might make them that much more aware of their future outcome. Instead what we see is people didn't know that they had diabetes, and then we see the foot ulcers, the amputations. And a lot of it was [because] they didn't know. So if we could catch them, even at a younger age, then [we could] provide a lot of teaching.

General physicians disagreed on the value of regular diabetes and foot assessments. Some physicians regarded foot assessments as a valuable prevention tool; others considered foot exams to be a lower priority relative to the treatment of acute problems. One physician suggested that foot assessments were better designated to other staff in a more specialized setting:

> MD: ..Check your foot for pulses, I probably don't do enough of that. Certainly, certainly a diabetic clinic where your hemoglobin A1C, your urine for albumin creatinine ratio, tuning forks on the, on the ankles and, uh, dorsalis pedis, posterior tibial pulses. Well those aren't hard things to do. Certainly all of that monitoring can be done by somebody or a series of people who take an interest in that sort of thing.

This physician questioned the effect of routine diabetes foot assessments on foot outcomes and amputation rates. Another physician acknowledged that regular assessment and foot care did have an impact on foot complications, but expressed uncertainty about whether more intensive assessment and monitoring of risk factors would improve disease prevention efforts.

In contrast, specialist physicians identified early intervention and aggressive management of foot lesions as necessary factors for the prevention of poor outcomes including amputation. One specialist noted that most uncomplicated diabetic foot conditions should improve with appropriate treatment, with some exceptions including diabetics with chronic renal failure. Specialist physicians upheld the value of foot assessments. Specialists described proper treatment of a foot ulcer as an art requiring time, experience and thorough assessment. Treatment decisions should be based on multiple factors including ulcer status, diabetes status and pressure measurements specialists indicated. One specialist suggested: "It's a bit of a judgment call too. So it's not cut and dry. It's common sense." Accurate assessment of a patient's vascular status was considered to be critical for effective management of foot ulcers. Specialists acknowledged that complete vascular assessment of an ulcer was time consuming and required special equipment and expertise. Pressure studies were identified as a valuable tool in the decision-making process of treating a foot ulcer. Critical ischemia, confirmed by absent pulses and low pressure readings, was distinguished as one important indicator for surgical intervention.

All physicians supported the provision of footwear as a priority in the upstream management of diabetes. One physician described the value of footwear in the spectrum of foot care:

> MD: ...If you want to have an impact on diabetics, then you got to go back once, you know, but before that you need to get in with the podiatry care. You know, all those guys should be given decent shoes. You know, what's the point of bringing of them down here, you know? We do a bypass on them. They go back, they still wear the same shoes. Okay, now they're in better circulation, you know. And then, you know, you got to get them earlier on but if they, if they have proper footwear, you're going to prevent most of the complications.

Another physician recognized investment in footwear as cost-effective: "You know $300 [for shoes] in the long run is definitely much cheaper than dealing with amputations, perhaps fitting them with more prostheses that they don't always use. And then having all the home care and everything else to support them at home."

Improvements in patient education were regarded as an essential aspect of diabetes care by many providers. One nurse recommended that diabetes education be expanded as a routine part of the care of all providers. A specialist recommended that diabetes education should at least be provided at the time of diagnosis. Nurses indicated the need for increased group level education. Physicians recommended a formal, standardized diabetes education program involving multiple providers including dieticians. Physicians agreed that diabetes education needed to be community specific and community directed. One physician questioned the quality and applicability of diabetes education provided and recommended more specific patient education on preventive care such as self-management of feet and footwear. Advocating a greater focus on primary prevention, physicians recommended increasing education on individual risk factors and lifestyle modification. Physicians believed that a major focus of diabetes education should be on "awareness raising" to assist patients in understanding the seriousness of the disease in order to promote better self-care. Providers supported early diabetes education initiatives, ideally targeting the young. One physician recommended that a physical activity program should be initiated in the school system with the goal of encouraging children to remain active throughout their lives.

Strategies for Coordinating Care

Timely referral of Aboriginal patients with diabetes, specialist physicians maintained, was critical for effective management of complications. Early referral of foot ulcer cases had a direct impact on outcomes, according to one specialist: "Basically, if you get a diabetic who presents early stage of non-healing ulcer, if you get him early enough, hopefully with antibiotics, local care, diabetic foot care, you might improve things. But, you know, we're seeing them weeks late." Early specialist care of patients in First Nation communities was especially urgent, specialists argued, because of the lack of comprehensive primary foot care in these communities. One specialist reviewed the criteria for referral of Aboriginal patients with diabetes:

> MD Specialist: No family physician is going to do [toe pressure tests] if they're not being paid for it. Bottom line. You know, half an hour at least. First of all, you've got to see a hundred patients a day, right. And then you're going to take a half an hour to worry about a guy's toe pressure when you can just refer him. So the bottom line is, I think what you need to do is that any person who's got tissue breakdown, skin loss, we need to see. I mean if there's no tissue breakdown, no ulcers, no gangrene, then the family doctor can handle it. . . . Most patients I see we're operating on them because of ulcers or gangrene. First, who should we see? I mean I think the bottom line is, the family doctors are too busy. And basically what they need is they need, once they see ulcers or gangrene, they need to get those patients assessed within a week. One week to 10 days. . . . Ideally, if you get a diabetic patient who's known diabetic who has any lesions on his foot [primarily that of ulcers and gangrene], I think in this environment, we should be seeing all those patients.

Continuing education for primary care physicians on criteria for referral of patients with diabetes was recommended by specialists. Specialists also supported continuing education of primary care physicians on foot care. Regular workshops for foot care providers on vascular assessment including Doppler pressure testing would also improve the quality of primary foot care in First Nation communities, one specialist suggested.

A specialist physician identified the need for greater personal communication from general physicians to ensure timely care of urgent cases:

> MD Specialist: Some of the nurses will say, the patient says he's got a gangrenous toe. You know, I turn over, when I hear about these cases. I try not to get, I try to get them in soon, within a week, ten days. And I think the message may be to the family docs is, if your diabetic patient who's got gangrene or ulcer is not being seen within a week, they should pick up the phone and say to the doc, listen, can you see this guy for me now. If not, there's [other specialists]. [They] should find someone.

Delivery of Diabetes Care

Physicians acknowledged the lack of an organized diabetes program in the community and offered recommendations for a preferred model of diabetes care. Physicians agreed that diabetes care in the community should be integrated in a specialized diabetes clinic setting where regular assessment, monitoring and education of patients could be provided by trained staff. As an alternative to costly, physician-run clinics, one physician suggested that a formal diabetes follow-up program could be managed by a team of qualified nurses with physician input on a consultation basis. Such a system, this physician suggested, would be time effective and improve triaging of patients. Physicians recommended that a diabetes program should ideally be managed by someone with a medical background who could enlist the support of the Band Council, and who could make a long-term commitment to creating a sustainable program. Supporting the recommendations of physicians, nurses expressed the need for a more specialized program with additional staff. One nurse remarked: "I would like to see a more comprehensive diabetes program with a qualified nurse and dietician. You know a health educator that would focus on that, and wouldn't be absconded to do maternal and child health, and that could set up workshops and education sessions."

Delivery of Foot Care: A Review of Systems

A forum, *Managing the Diabetic Foot*, was held on March 23, 2004 at two rural hospitals for health providers who served the community. The forum was organized in partnership with a vascular specialist from Winnipeg with the intent of bringing together key provider stakeholders of foot care in the community to review foot care delivery, to establish consensus on benchmarks of care and to plan new strategies for optimizing foot care. Forum meetings also provided an opportunity to facilitate continuing medical education between specialists and primary care providers.

A total of 32 individuals attended the forum. Participants included nurses, specialist and general physicians, physiotherapists, occupational therapists and health administrators. The forum began with a presentation on diabetic foot assessment and management by the vascular surgeon. This was followed by a brief update on the status of foot health and foot care in the community from the recent literature and this research project. A group discussion and strategizing session concluded the forum. Group discussions centred on preventive, primary and tertiary foot care. Participants addressed standards of foot care, care paths, and action plans for improving foot care in the community. A summary of the key issues and recommendations generated by the forum is included in Table 9 below.

Discussions on preventive foot care included a review of foot assessment in the community. Foot care nurses, home care nurses, health care aides and physicians were identified as the main providers of foot care in the community. Physicians noted that foot assessment results of other providers were not easily accessible due to separate charting systems. Providers agreed to begin streamlining patient records by including nursing foot assessment reports in physician charts. Administrators proposed a monthly community foot clinic for regular provision of diabetes foot assessment and foot care. However, there was no consensus among participants as to who should assume major responsibility for the provision of routine foot examinations of patients with diabetes. Some primary care physicians indicated that diabetes foot exams were not a priority in the scope of care they provided. Primary care physicians maintained that upholding general standards of diabetes care in the community was unrealistic. Advocating for higher standards of foot care, specialist physicians asserted that ankle pressure testing was an essential aspect of a complete foot assessment. Administrators and general physicians put forward a proposal to purchase a Doppler ultrasound unit for the community health centre. Specialists agreed to facilitate this training for nursing staff. Some administrators expressed concerns about the ability of the health care system to manage increased foot screening. These administrators were not receptive to the suggestion of increasing training of allied diabetes providers to include foot assessments. Foot assessments were not considered to be a part of the ADI program mandate of prevention according to administrators.

Proper footwear was acknowledged by all providers as an important tool in the prevention of foot ulcers. Providers discussed the barriers to accessing appropriate footwear. Administrators pointed out that, for the average resident in the community living on a fixed income, new shoes were not an affordable option. Several physicians requested clarification of the guidelines and criteria for obtaining subsidized footwear under FNIHB's Non-Insured Health Benefits Program. Physicians questioned the reliability and availability of quality footwear suppliers. Participants proposed circulating information to all foot care providers on footwear coverage guidelines and recommended footwear suppliers. Physicians and administrators agreed that continued pressure should be put on governments to improve footwear funding policies.

Upon reviewing primary foot care services, participants addressed wait times for basic foot care in the community. Physicians recognized the need for improving preventive foot care. Providers acknowledged that existing foot care services were not accessible to enough residents, and were not attracting residents at an early stage. Nurses proposed reinstituting foot care nursing services at the Health Centre on at least a monthly basis. Administrators agreed to provide transportation services to the health centre for patients requiring foot care.

Participants reviewed the role of specialist physicians in the delivery of foot care. Specialist physicians encouraged early referral of diabetes patients with foot problems. Receptive to consultation from both nurses and physicians, specialists reviewed referral procedures. In urgent cases involving patients with advanced foot complications, specialists recommended personal referrals by telephone to expedite care. Specialists also clarified the criteria for referral of diabetic patients with foot problems.

Table 9

Forum on Delivery of Diabetes Foot Care: Summary of Provider Recommendations

	Key Issues	**Key Recommendations**
Foot Assessment	▪ Need for exchange of foot assessment records between disciplines ▪ Lack of consensus on who should assume responsibility for routine foot examinations ▪ Feasibility and value of Doppler ultrasound testing ▪ Capacity of the health care system to manage increased foot screening	▪ Streamline patient records o include nursing assessment records in physician charts ▪ Build capacity o Provide Doppler ultrasound training for nurses
Footwear	▪ Value of footwear as a prevention tool ▪ Affordability of footwear ▪ Appraisal of funding for footwear ▪ Unclear guidelines and criteria for footwear coverage ▪ Quality & reliability of footwear suppliers	▪ Knowledge exchange o Disseminate footwear coverage guidelines o Disseminate list of footwear suppliers ▪ Policy change o Lobby governments for increased coverage of footwear
Primary Foot Care	▪ Access to basic foot care ▪ Wait times ▪ Need for early foot care	▪ Improve access to existing services o Increase clinic-based foot care services o Facilitate local transportation for foot care
Urgent Foot Care	▪ Role and place of specialist foot care ▪ Access to specialist care	▪ Knowledge exchange o Clarify criteria for referral o Clarify referral procedures

4.3E SUMMARY OF THE HEALTH CARE ENVIRONMENT

Patterns of Practice

Primary care providers exhibited variable styles of practice and generally worked independently of each other in the community. Primary diabetes care in the community did not consistently meet clinical practice standards. Routine diabetes screening was not available. General physicians performed occasional, incomplete diabetes assessments. Nurses and specialists were critical of the quality of diabetes management practices that focused on symptom management and involved inadequate medical therapy.

Foot care comprised only a small part of the practice of diabetes providers. Almost no one appeared to be providing regular foot exams in the community. Primary foot care was typically initiated after the development of significant complications. Primary physician care of advanced foot complications ranged from independent medical treatment of outpatients to more comprehensive inpatient care. In general, family physicians and nurses referred few cases of foot complications to specialists. Using more conservative referral criteria than specialists, nurses and family physicians tended to refer cases of foot complications at a relatively late stage.

The practice of primary foot care providers was a product of individual values and independent work styles, as well as demanding work conditions in the community. All providers reported seeing high patient volumes. Both primary care providers and specialists saw a wide spectrum of foot problems with a high proportion of cases presenting at an advanced stage – when treatment was deemed to be relatively ineffective. Nurses were overloaded with increasing administrative demands.

Community diabetes workers had inadequate clinical training and received little professional support. Physician practice in the community was constrained by a lack of space, time, and medical supplies. Under these conditions, primary care physicians indicated that they could not and did not consistently meet diabetes practice standards in the First Nation community setting. Physician payment systems directly impacted quality of primary of care in the community. Fee-for-service physicians were less likely to meet diabetes standards of care than salaried physicians as they tended to see larger caseloads with less clinical support.

Lack of provision of foot exams in the community was explained by primary care providers as a matter of individual priorities and expectations, as well as a response to a challenging work environment (Table 10). Conservative treatment of advanced foot complications was rationalized by general physicians on the basis of age, and perceived compliance and expectations of patients. Lack of timely primary care management of foot ulcers, according to specialists, was also a reflection of the complexity of the clinical decision-making process.

Providers offered multidimensional reflections on the practice of amputation. Physicians appreciated amputation from the point of view of the patient as both an unfavourable outcome that conferred disability and as a humane option that alleviated pain and suffering. In the context of the health care system, amputation represented a failure of preventive care, but also served as a practical solution that moved the problem of foot complications out of the costly hospital system. From the perspective of the surgeon, the decision to amputate remained a fine balancing of risks and benefits.

Table 10
Provider Explanations of the Limited Provision of Foot Exams in the Community

Demanding work conditions did not support preventive care ▪ High patient volumes ▪ Lack of time ▪ Cases present with relatively more urgent problems ▪ Cases present with multiple problems
Diabetes practice standards are not applicable to First Nation community setting ▪ Not practical due to limited resources ▪ Not feasible in fee-for-service practice
Foot assessment and foot care were not a high priority ▪ Value and effectiveness in prevention questioned ▪ Viewed as outside mandate of prevention ▪ Viewed as a small aspect of preventive care ▪ Acute care deemed a higher priority ▪ Patient education deemed a higher priority
Perception of patients as not invested in care ▪ Patients did not seek early foot care ▪ Patients perceived as having low expectations ▪ Patients perceived as noncompliant with appointments and treatment
Few diabetes providers had specialized training in foot care

Participation in Care

People in the community did not get on “the assembly line” or participate in the primary care system in the manner that providers expected. People did not seek primary care in the community on a regular basis. Instead they occasionally visited a family physician outside the community, or visited several physicians at different sites. Some opted to visit traditional healers. Providers attributed poor foot outcomes to lack of continuity of primary care within the health system.

Few people sought early primary foot care in the community. Many visited physicians after developing serious foot problems. Lack of appreciation of foot problems, difficulty accessing family physicians, and beliefs in reserving physician care for serious illness were common explanations for late visits offered by both providers and people in the community (Table 11). Many sought foot care in surrounding hospitals in outpatient clinics and emergency departments. People also reported frequent hospitalizations for foot complications.

Table 11
Explanations of Limited Participation in Early Primary Foot Care in the Community

Limited access to foot care providers* † ▪ Difficulty accessing family physicians* † ▪ High turnover of family physicians† Limited pool of foot care providers†
Lack of knowledge and awareness of disease* † ▪ Underestimated seriousness of foot problem* † ▪ Lacked awareness of bodies† ▪ Asymptomatic in early stages of disease†
Belief that family physicians should only be seen for serious illness* †
Dissatisfaction with quality of physician care* ▪ Physicians perceived as too busy ▪ Physicians perceived as inattentive
Value of independence* ▪ Preference not to be too dependent on health system ▪ Self-reliance
Foot care a lesser priority† ▪ More pressing concerns regarding food and housing
Lack of formal education†
Lack of initiative†

* Explanations of people with foot complications
† Explanations of providers

Several interesting contradictions around the position of people in the community emerged in the narratives of participants. The contradictions were deliberately juxtaposed in the results to reveal differing perspectives between stakeholders. In the case of knowledge, providers generally believed that people in the community lacked an essential understanding of diabetes in terms of risk factors and development of complications that impeded them from properly caring for their feet. Some physicians believed that people also lacked an awareness of their bodies. People themselves did admit to underestimating the seriousness of early foot problems. Most, however, were acutely aware of their symptoms describing them in great detail. People also revealed a multifaceted understanding of illness that was primarily shaped by experience. All people with foot complications appeared to have a strong appreciation of the seriousness of diabetes from both an experiential understanding and from witnessing the suffering of family members.

A second contradiction emerged in the dichotomous ways that people participated in care. People in the community were viewed as adopting both a passive and proactive role in managing their health. These contradictory roles may be explained by examining the position of individuals inside and outside the health system. Provider perceptions of noncompliance were based on how people adhered and accommodated to medical care within the health system, and did not account for what people did at home. For example, many providers were unaware of the fastidious, disciplined manner with which some people managed foot ulcers on a daily basis in their homes, as these people were not visible within the health system.

People in the community were perceived as being noncompliant mainly with medication and medical appointments. In many cases, missed appointments appeared to be less a matter of compliance than an issue of access. Lack of reliable and wheelchair accessible transportation, lack of a telephone and the limited availability of physicians were some factors impeding people from visiting physicians. Alleged noncompliance of patients with specialist appointments by some primary care providers was in fact negated by patients, administrators and specialists, and appeared to be a less significant factor than physician referral practice in explaining low rates of special visits. Many people with advanced foot complications were treated independently by their family physicians and were not referred for specialist foot care. The contradictory understandings of the position of people in the health system thus reveal a fundamental disconnect between providers and people in the community.

Performance of Health Systems

Diabetes care systems in the community were disconnected and did not function in a coordinated manner. Diabetes services lacked a central administration and were delivered in a piecemeal fashion. Medical information systems were not linked and not easily accessible to providers. Providers worked independently from each other and from the community health administration.

Primary care in the community was dominated by an acute care model, leaving little place for the management of chronic disease in the system. Preventive care systems consisted mainly of patient education initiatives. Some providers were critical of health education messages that focused exclusively on self management of diabetes but failed to address structural barriers facing community residents.

The primary care system lacked sufficient capacity to meet the demand for diabetes care. Nurses providing diabetes care were overloaded with both clinical and administrative responsibilities. Patients had difficulty accessing physicians on a regular basis. Few diabetes providers had advanced training in foot care.

Foot care services in the community were not easily accessible. Primary foot care services, available on a limited and irregular basis, could not adequately meet the demand for foot care in the community. Few staff in the community provided foot care. The administration of foot care was highly bureaucratized. The referral process for basic foot care involved several mediators and ended in a lengthy wait list. Triaging and scheduling of patients with foot problems remained a closed process that providers had difficulty accessing. Local transportation systems were not wheelchair accessible. Consequently, few people were able to access basic foot care services in the community. Access to specialist foot care was also delayed or limited by the conservative referral practice of primary care physicians.

Appropriate footwear was difficult to access for many people in the community. Many had difficulty finding a comfortable pair of shoes that fit properly. Most people in the community could not afford the shoes they were prescribed. Few were eligible for subsidized foot wear. Those who were eligible experienced long wait periods for shoes.

Thus, we find a health system functioning in a state of crisis. The primary care system in the community lacked adequate resources to manage disease at an epidemic stage. Resources were skewed mainly toward acute care and primary prevention leaving the progression of foot complications virtually unchecked. The limited resources that were available for foot care were not easily accessible within foot care systems that lacked fundamental connections and coordination.

4.4 THE INDIVIDUAL CONTEXT

4.4A. THE ROLE OF THE INDIVIDUAL

Individual Risk Factors

Providers considered control of individual risk factors for diabetes to be an important aspect of managing peripheral arterial disease and an essential aspect of diabetes prevention. Genetic factors, smoking, a high sugar diet and insufficient exercise were associated by physicians with the development of diabetes complications. Physicians viewed the lifestyle and behaviour of individuals as major contributors to the problem of diabetes complications. Tobacco smoking was associated with the culture of the community – a factor implicated by one physician in the rapid progression of disease in the community:

MD: Plus they have the use of tobacco. The principal of the school,[...], described to me that, 'Well, you do something for somebody, they give you tobacco. You go over to somebody's place, you have a cigarette. It's just part of our culture, it's what we do. We smoke.' And I do believe smoking and diabetes are a horrible complication or a horrible, sorry, combination. ...I think the progression there is quicker than elsewhere, whether that's genetic, or genetic on top of a culture which hasn't adapted to their current situation? A culture is a tool that helps you relate to and deal with the world. If your culture is appropriate, it's a successful way of dealing with the world. And your mother teaches it to you before you're 4 years old. And if your culture is maladapted, it doesn't work well.

Unhealthy diet was singled out by both providers and patients as a major problem in the community. One physician observed that although some people in the community incorporated wild meat that was low in fat into their diet, most youth consumed a high fat diet including potato chips and pop. Providers speculated that the poor diet of community residents stemmed from an addiction to sugar:

MD: ...I think there's a genetic predisposition there, on top of a terrible diet. I think there's a craving there for sugar there that knows no bounds....there's a Coke machine right in the Health Centre. And it shouldn't be there. There's uh, how many of the kids come in with a constant infusion of sugar. And I'm sure many of the kids are insulin resistant and prediabetic.

Administrator: I knew these people, you know, there was a lot of sugar, in their coffee. Five, five teaspoons would be no problem for them. You know. Then they drink alcohol. They drink like crazy 2 straight, 3 months straight, you know. All these issues that are attached to diabetes okay, results from a long, there's a long standing history with, with, uh, government. And then there's, uh, abuse issues, you know, comforting, it's something sweet. A lot of people are hooked on chocolate, for example, or Pepsi or Coke, you name it, you know, chips. Something that'll comfort them. And then there's all the white stuff that are not good for us like flours and sugars, you know. People eat an enormous amount of bannock, you know, spongy stuff. . . . They eat that morning, noon and night. . . . They eat it to excess. Eat it to excess and, and there's also some form of illness, you know. Obesity. You see a lot of our people, a lot of our kids walking around. I know one kid, he's at least 200 pounds.

People were equally critical of the food choices of others in the community:

Patient: So they still maintain the diet they had before they had diabetes. I guess that's what led to diabetes. . . . It's mostly diet. Like people, right from day one when I came on the reserve, they really liked a lot of lard on their bannock. Too much grease it builds up fat in the arteries. This is where it starts from.

Oh if they could get away with that much lard or grease it would be okay. You should see them. They lay about half of an inch of lard, gallons of tea, which is hard on the kidneys.

Patient: There was never used to be any diabetes until about twenty years ago here in [the community]. A lot of people used to eat wild stuff, a lot of meat. Like muskrat, they used to eat muskrat. Beaver. Now we're eating store bought like canned stuff. I think that's what's causing a lot of sickness from the, like from the canned stuff. Like beef stew, it's already cooked and they can it. . . . There's too many pre-cooked foods. You just have to heat them up in the microwave. You don't know what the microwave does eh.

Patient: I'm always watching what I eat. Cholesterol, I gotta go down on my cholesterol. So I watch everything, eh. It's what you eat I guess. Us people are, like Indian people, what they've been eating they like eating. There's no way you're gonna stop them. [laugh] That's just the way they are. . . . Most of them they'll just eat what they've been eating and some people'll just still use lard. They still use fat and I tell them no.

Ironically, medication served as an incentive for engaging in poor eating habits according to providers. One physician observed that patients who had been prescribed medication often made unhealthy food choices because they believed medication afforded them extra protection. A nurse made a similar observation: "...Some people think that when, if they're diabetic and they go on medication, they think it's okay then again to eat whatever you want just because they're on medication."

Individual Responsibility and Choice

Providers viewed patients as having a central role in the management of diabetes and diabetes foot complications. Many providers viewed the lifestyle of people in the community as a matter of choice. One general physician rationalized that effective diabetes management was a matter of individual choice because patients in the community had easy access to diabetes testing. Community residents made conscious choices to smoke and eat junk food another physician argued. Failure to adopt a healthy lifestyle was interpreted as a matter of compliance by one nurse.

Preventive foot care was ultimately considered to be the responsibility of the patient and the_community according to physicians. Community members needed to accept greater responsibility in managing their health according to one Aboriginal administrator:

> Administrator: …I think, um, teaching the community too, to take responsibility for themselves [is necessary].. Like I know through our program because we were doing everything for them. We were setting up their appointments, blah, blah, blah, blah, blah, everything else. Now finally we're saying, you know what, no you make, you phone and make the appointments because then what was happening is they wouldn't go to that appointment because they knew we were going to phone and make an alternate appointment. So it got to that point where we were just like, no, you know what, we'll help you and tell you what to do and where to go, but you have to take on that responsibility because it's your health… And then just teaching them that kind of thing. And then having also, um, the authority figures to back your decision and saying no to some of the clients that are taking advantage of some of the stuff. Because that's where the big problem is. There's so many people taking advantage of different things.

Women were distinguished as agents of change in the community because they were thought to take greater responsibility than men for medical appointments.

Indeed, patients accepted much of the responsibility of managing diabetes and maintaining good health expected of providers. One patient noted, "“I got high blood pressure, eh. I got high blood pressure, diabetes, arthritis, asthma. . . . So all those diseases I got, I have to take care of them. Eat the right foods." Patients who had become self-reliant in managing their health often expected that all people in the community ought to take care of themselves. In fact, both diabetic and non-diabetic residents were critical of individuals with diabetes for not properly caring for their own health and/or for seeking professional care:

> Patient: I'm glad I'm not a diabetic. I do, uh, I'm careful what I'm eating. I never have junk food.

> Patient: If a person has the, has the spirit to go on, [it's] not hard to take care of yourself. But every person's different. Some people tend to want to be served hand and foot just because they're a little bit sick, but that's individualism.

> Patient: They have so much problems with their feet, the people. But, uh, that's where the problem is all the time. Their toes and their legs or whatever…to be cleaned or cut their nails or keep their feet clean or dry. I mean, like their feet get very dry and they're cracking and everything they get sores, eh. I never get myself in that position. . . . They don't look after their feet. They get all dry and crack and they get sores and everything. I don't know.

Patient: I do a lot of walking too for exercise and that. And I think maybe people should do that too once in a while and look after themselves, not just give up, somebody to come in an look after them, you know.

4B. RESPONSE TO DIABETES

Response of Providers to Diabetes

Physicians were generally overwhelmed by epidemic conditions in the community. Several general physicians admitted that they could not effectively manage the high demand for diabetes care in the community without greater assistance from other providers. Response to the disease was typically one of frustration:

MD: Diabetes. It's terrible. Diabetes control is terrible. It's not as good as it could be. There's community strategies, there's individual strategies. Using physicians, using nurses, using diabetes educators, all of those things are being done. And yet, it seems like the more we do the worse it gets. . . .I've been there long enough to watch people go from being quite asymptomatic to renal failure, blindness, um, dialysis, death. I've watched that quite a bit. And, and I feel frustrated because I don't think I'm doing very much for them.

Providers also expressed a sense of fatalism and resignation to poor health outcomes. One nurse questioned the effectiveness of treatment of patients with advanced foot complications_was limited: "...I have found that people that have gotten into the advanced stage, there's really not much you can do. Their circulation is already been, it's already been so damaged so much that there's really not much you can do." One specialist predicted that most First Nation patients with diabetes "are going to get into problems." Intervention was deemed ineffective in certain cases. In cases where diabetics had developed both foot complications and chronic renal failure, amputation was almost inevitable according to specialists. The prevailing pessimism of physicians about health outcomes was transferred to patients as evident in one physician's message to a patient: "You've got poor circulation in your legs, your diabetes has caused this and it's going to cause you trouble in the future. Okay."

Provider Understandings of Patient Response

Denial of serious illness was identified by providers as a common characteristic among patients with diabetes who were resistant to early preventive care:

> Nurse: ...People do not do anything about their health until they are incapacitated or not feeling well in some way. So, even though we have had two prevention programs and have tried to encourage people to do things to improve their own health, it seems that the overall milieu of the reserve, it's sort of, everybody just sort of lives day by day and almost like, well whatever happens today but if I get sick tomorrow then I'll go to the doctor tomorrow. But I don't have to do anything today in order to get, to feel better tomorrow. There's a denial. I have seen that in clients where, you know, I know a long time ago for instance I did a screening. Just, I used to go to the band office in the old days, it was, the set up was different. I'd go to the band office and I'd just meet them at the door and yank them in and do just as many people as I could get, because everybody hung out there. And one fellow that I did find, was very, refused to have anything to do with, like, you know, he, because I think it was more like an, it appeared to be denial. And, again, people just don't feel the need to do anything until something happens you know.

> Nurse: We need to change their attitude, people's attitudes. I don't want to see them when they're sick. I want to see them when they're well. That needs to be done. I imagine you had plenty in the past, 'oh I feel fine, there's no problem you know.' Their sugars are 22, yeah but you know, c'mon. Down the road you're going to come crying to me. And I've had people with diabetes, I've worked with them, and then I struggled with them, and I've talked to them, and I was patient with them. And this one only guy, I come in to his house, and this is after he lost both his legs, his eyesight, and he's on dialysis, and he says, [nurse], he says, you know all those things you said to me, you were right. And I'm thinking, what good is that now? . . . Denial, anger, the lifestyle, you know.

Stress often overshadowed the problem of diabetes in patients' lives, one physician observed, "I think that they have so much stress living from day to day that you know like a common disease like diabetes, it's put on the back burner."

Physicians observed a general resignation to poor health among patients with diabetes. Attitudes of hopelessness and resignation surrounding diabetes contributed to a collective inertia within the community according to one nurse:

> Nurse: Some people think that when they get diabetes that it is a sentence. That's the way they're going to be so why bother fighting it, it's going to be there. Just make the best of it. . . . I've never seen some, like so many people in a way, maybe, maybe that's because I've been here too long, I don't know any more what's happening out there, but lacking of imagination. And I've told people, you know what's become of us here? These are people without a dream. We don't dream any more. We don't hope. We don't hope. We don't dream what could be, any more. Where do you go with that? You go nowhere. . . . So like how do people maintain hope? If you do not have hope, you do not have the energy to take care of yourself. If you do not have the energy to take care of yourself then you get sick and then all of a sudden you're afraid because you can't do the things that you just, you can't feel well, and in your misery you can't feel well and maybe, you know, take care of your house.

One administrator pointed out from personal experience that individuals experienced loss of hope in different ways: "It's difficult for some. They go through a depression. Like one of my brothers went through a depression when he found out he's diabetic, but he bounced back. But the other one is like, 'oh I'm gonna die anyway, why bother?' And yet he's younger and the one with the most potential to have I guess a better life...."

Resiliency was evident in some exceptional individuals. One nurse recognized the remarkable fortitude and defiance of one survivor of multiple complications of diabetes:

> Nurse: ...One fellow, he made me wonder. What he was saying is that like he had his, you know, his amputations, also problems. He had everything amputated, and he was blind. And it was almost like, 'see what I've survived. I'm still living and I survived.' That's a different way of looking at it: 'I've survived, like I have managed with all of this stuff, I am still breathing.' . . . it was something very hard but. . . it hadn't beaten him. . . . Well you know, and it makes sense in a way. If you haven't got anything, you have a very meager and you've accepted that. And then you have all of these other things and you've managed to, you're still breathing. You know on the outside I suppose what we would have, if we did, if we had all those things happen to us, we would think well I can't go to work. I can't do this, I can't do that, I can't do this. The fact of being maybe housebound would be a terrible thought. The fact of being dependent on somebody would be a terrible thought. Losing your, losing control of independence. I'm sure those things actually do have an effect on the person. But in that one individual there, I think that in some ways it's a victory. . . . The other thing is he had his mouth and he used it, which was good. . . . He sometimes used it in very derogatory, like demanding things. And, you know, like sometimes we would get upset. He was blasting me already, you know, whatever. Then I look and that's the only means of control he has. He has no other controls. He's 100% care. He has no way of controlling anything in his environment, including his own body. So he demands and stuff like that and I thought, you know, he's actually, like he's not doing it in a very good way, but he's actually trying to show that he does have some control over some things by trying to control you and your behaviour. . . . I'm amazed at how well sometimes people do put up with the disabilities that they have.

Response of People to Diabetes

The impressions of diabetes of individuals in the community and their responses to the disease were varied and complex. Response of the community to amputations was mixed. One resident suggested that people in the community had become desensitized to the practice of amputation due to its increasing occurrence: "Like the amputation people out here. The way they talk, it seems like it is so easy. Like, like one of these ladies, she said I'm going to go get my big toes cut off tomorrow, she said like. The way she was talking, it sounds so, so goddamn easy. You know what I mean? ...It's no big deal.

Cause they laugh among one another." However, resistance to amputation as a treatment option was also evident in the community. One amputee noted, "People, other people have had [foot problems], but it was fatal for them because they didn't let the doctor amputate their leg. . . . They had that ulcer on the ankle. They would, just wouldn't let the doctor cut their leg off. Oh I'll heal, I'll make it heal. Didn't." This individual recalled the case of a cousin who had developed a seriously infected foot ulcer but "wouldn't let the doctors cut his leg" until his relatives convinced him otherwise. The outcome of amputation was regarded with considerable gravity by residents who had witnessed the suffering of family members with foot complications. One individual reflected, "Well my brother, had to get his legs amputated. Both of them. That was a hard thing. It was even hard for me to see him. He was so young and just. . . . He was the one that was in a hospital quite a few times. He was the one that really suffered so much. . ." Another individual recalled how her sister's experience with amputation affected her own early experience with a foot ulcer: "I was scared. I used to see my sister what, awful. Her bones. . . . Her leg got cut off. . . . The bones used to fall off. The bones in your little feet, in your little toes. . . . Yeah. They keep falling. . . . Oh I saw what she went through. I didn't think I would be able to go [through] that either." Patients struggled to cope with their own foot problems as they recalled the suffering of family members. Like providers, patients were overwhelmed by the task of managing chronic foot problems.

Fear of both the inevitability and unpredictability of diabetes was apparent in the narratives of many patients. Fear served as both a motivator and a deterrent to seeking foot care. "I used to get about a yearly check-up. . . . Yeah, because I was scared of [diabetes], eh. I knew I was gonna get it…", recalled one individual who was eventually diagnosed with diabetes. One amputee reflected, "But that's the way they are, people here. They won't. They start to see a doctor about something, that's the way they do it. I know most of them. . . . They won't go until it's too late for something. . . . I don't even know why. Just scared of a doctor I guess, some of them."

Several patients with diabetes expressed a deep hatred of the disease as a result of the physical discomfort and hardship they had experienced with illness. Quick to disassociate the community from the disease, a non-diabetic resident revealed the underlying stigma of diabetes:

Patient: Well it's not only this community that are diabetic. It's all over the world, you know. All over. In the States, any place you go there. It's diabetic all over the place. So the people shouldn't feel [badly] about it. They're not , the Indian people are not the only ones that are diabetics. They're all over the place.

Congruent with the impressions of providers, patients expressed a sense of resignation about living with diabetes and the associated complications:

Patient: Ah, I went in and got it checked and then... That's when I started having diabetes. I wasn't at the borderline, I was, like it was too late for me to try and do something about it .

Patient: For me, it's okay. . . .I accept the pain already, eh. Nothing I can do about that.

Feelings of hopelessness and despair were common among patients experiencing multiple complications. One resident observed:

Patient: Lot of people, if they get sick then they just let them go, let themselves go. Know what I mean? ...There are a lot of people been giving up out here. I don't know what's wrong with them. ...one of my uncles just passed on last week. ...And his leg was amputated. He was going for dialysis and he didn't want to take dialysis no more. Just let himself go. Just died at his home. They think they can't do nothing when they have like, when their legs are amputated. Like they can do a lot of stuff when their legs are amputated. They just have to depend on everybody.

Stress was identified as one reason why many patients in the community gave up on their health. This point of despair was often precipitated by major events including prolonged illness, death of a spouse, as well as amputation. In some cases, amputation appeared to rob individuals of the will to care for their health. Feelings of hopelessness appeared to deter some from seeking primary physician care. One patient recalled the case of an elderly acquaintance:

> Patient: His family took care of him too but, uh, he's not, he wouldn't even go to the doctor too at times, eh. ...He was, probably was giving up too. ...I see a lot of that. I know, that's why they die. They gave up. ...They've had it too long, I guess, it just. A little bit of something that would make them give up, eh.

Resiliency was observed in a few individuals who remained remarkably optimistic after amputation. One individual described life with diabetes as "a hard life, but still a good life." Some amputees were simply grateful for their lives and even retained a sense of humour. One individual joked, "I still have my life but no legs. . . . Well I'll get artificial legs. I'm hoping by next year, I should be golfing." Another individual expressed mixed feelings about his amputation: "I'm managing better now ever since they cut the leg off. . . . There's a lot of things I'd like to do, but I can't do that because of uh of limited...I don't have no legs, and then my fingers are missing and things like that eh." The optimism of these individuals was often mixed with pragmatism, possibly contributing to their resiliency:

> Patient: Well I need my other leg but [laugh]. . . . Can't give that. I have to do the best I can with the prosthesis.

> Patient: Well I don't find it challenging. I find it's an everyday life thing to me okay. You either bust or stay with it you know. . . . Oh it's a hard life, but you gotta go with the flow, you know. You cannot feel sorry for yourself. You cannot let yourself uh run down you know.

The optimists remained philosophical about life after amputation. One individual reflected, "People have good ideas but sometimes they don't work out the way they plan or what. It's like everything in life, sometimes you plan and then it doesn't work out that way."

4C. KNOWLEDGE, UNDERSTANDING AND AWARENESS OF DIABETES

The Position of Providers on Knowledge

Multidimensional understandings and interpretations of patient knowledge of disease emerged from provider narratives. Lack of patient knowledge about diabetes was considered by physicians to be a significant barrier to effective management of the disease. Physicians speculated that patients had an incomplete understanding of the disease either because of inadequate education or because of the unwillingness of patients to learn or do more for themselves. A physician suggested that patients were not invested in managing their disease because of a lack of knowledge of self-care. Another physician observed that despite education efforts, patients did not fully understand individual risk factors and the development of complications; this physician speculated that sociological or psychological issues were involved. Other providers suggested that most patients did understand the significance of controlling risk factors, but lacked an understanding of primary prevention of the disease.

Ignorance of disease complications was linked to denial according to a nurse: "My experience is that their, their level of knowledge of the outcomes is very poor. I find that they see and we can teach all the time but until something happens to them, it's just, it's almost like they don't believe it'll ever happen to them." Reflecting on family experiences, one administrator concluded that internalization of information about diabetes was a gradual and individual process:

Administrator: ...The community members themselves [have] to take the initiative and say, okay, this is what I wanted to tell myself. Even though they're being educated constantly, it takes a while before it kinda actually sinks in. Like, I'll give you a good example. My brother. I come from a large family. And they're all diabetics.... My brothers there were both diagnosed together. Two of my brothers. And one kinda was in the denial stage and refuses to help himself even though he's been educated, he knows what's going to happen. And then there's the other one that's working really hard to look after himself. And I see a lot of that. And then even though the education was there, they realized that, okay, eventually we're gonna, if

> they don't look after themselves, we're gonna be diabetics. . . . So, even with the education, it's just, the people having to take the responsibility and look after themselves.

Language was also believed to impact patient knowledge of diabetes. One physician speculated that people in the community who did not speak English had a poor understanding of diabetes and also experienced greater health problems than English speaking residents. This physician concluded that fluency in English was an important condition for understanding the disease and preventing disease complications:

> MD: I've met a few rare ones and you still see them now and then, who's language is so poor that, um, they don't understand the disease because. And this is really important. I'm thinking about this. I don't think there's any concept of diabetes, of peripheral neuropathy, vascular disease, etc. in the Saulteaux language. So to understand the concepts, you first have to have the language. You have to have some English. The people that seem to do best, if you look at the healthiest people there, this is an interesting thought, they also seem to have a good understanding of English. I've had a few patients die because of lack of English. They, they couldn't speak English, ok, well use a translator, what's the problem? But, that's not the problem. Is that the English also has the concepts with it too. I don't think the Saulteaux language has a concept of hypertension, diabetes, vascular disease, nephropathy. I don't think those words are, there's no diabetic, or there's no Saulteaux work for nephropathy. So to understand your disease, you have to have the words. And if you don't have the words, you can't understand the concept. ...Because if the concept isn't there, it's very hard to get that concept across. I think if you maybe looked at the people who do fairly well with their diabetes, almost everyone speaks good English. Those who don't speak good English, maybe they don't do as well. ...But, on the other hand, I think you'll find some very smart people there, who understand it very well. And I think they tend to do better, because they can do better. They understand oh, this is diabetes. Diabetes leads to kidney disease, and it all depends upon the English language sadly.

Providers disagreed on whether patients fully appreciated the seriousness of the disease. Some physicians believed that patients did not appreciate the significance of controlling their glucose levels. Individuals with diabetes who were not compliant with education lacked an understanding of disease consequences, one administrator concluded:

> Administrator: They don't understand that [they can lose their feet]. We have some clients out in [the community] who refuse treatment period. If they're getting blind, or if their legs are gone. It's poor compliance, or else like, uh, for example, somebody that's on fluid restrictions that's diabetic, like what I've actually done was they're on a one litre fluid restriction. So I took a one litre water bottle with them and I told them, to explain to them, like every time you're going to drink something, pour the same amount as this bottle. And this bottle's full, you can't drink any more. Because drinking one litre and then drinking a cup of coffee here and there. Well they've had that one litre bottle filled by 10 o'clock in the morning and it's continued and then, so the next day, dialysis is phoning and saying, 'oh we drained five litres off, aren't you guys teaching them?' . . . . And even the teaching, now because they can't say they're not being taught. . . . Like even dressings, like a packing to do and then the nurse [will] go in and this person sticks in their hand with like cranberry juice and like, we're like oh. Like you know what I mean? And we're trying to teach them, no you're going to get an infection. Or if they have a spot that has gangrene, [we ask them]

> please don't soak it, keep it dry. Like it has to be kept dry, then you go there the next day and they've already had their foot in the water for two hours.

Another administrator pointed out that lack of appreciation of the seriousness of the disease was less an issue for people managing diabetes than was the stigma associated with the disease:

> Administrator: [People take diabetes more seriously now] because there's, they see more and more amputations and the struggles that these people [in the community] have . . . .They realize that this is a serious disease. And they realize, okay, this isn't something I should have wished for but now that they have it, there's other challenges. Like, for example, for [people employed as] drivers. It was that, if you are a diabetic, you shouldn't be driving because what if you, say you have some problems with your disease, that kind of thing. So, and then what would happen after that was people would start hiding that they do have it, the ones that want to work.

One physician observed, "The biggest problem is self-awareness. That's the single biggest problem. The rest is easy. Most of the people there know...I think know enough to deal with their disease once they have an appreciation of the fact that it is a disease." Another physician questioned whether patients had a distorted perception of the healthy body that was culturally based:

> MD: I don't know about this or not, but whether or not culturally if you see somebody who's thin, if there's any kind of a stigma associated with that. Where you see somebody who's a little bit obese and rotund. Because we get lots of people saying, "What's wrong with my kid. He looks sick and skinny". But he's not. He's a totally normal healthy child. So I wonder if that carries to say that somebody who looks, we would call obese or well fed, whether or not that's viewed in a more positive light than somebody who's got a body mass index of 21 and thin.

People with Foot Complications on Knowledge

Patient knowledge of diabetes was both simplistic and sophisticated. One patient indicated that diabetics in the community lacked sufficient knowledge and education about diabetes management which contributed to their stress: "They're all stressed out some of them, eh. Cause most of them don't know, they're not really educated in that what could they do, it's all about it. They're not really educated about it, so they don't know what it does and what's, what's, what is it. I think that would be good for them too." Other community residents appeared confident in their understanding of the disease. When asked about his experience with diabetes, one patient asserted: "I understand why I feel it, and what I want and what it doesn't want." Several patients showed initiative in informing themselves about diabetes. One patient revealed, "I read all the books. I got so much books in my house. I read all [about] what I could do, what is there, what kind of herbs should I take, what I'm supposed to eat. All that, that's what I'm trying and doing now." Another patient indicated that he had begun reading medical books to learn more about diabetes and the medication he had been prescribed.

Patient understandings of the disease were multifaceted. Patient understandings of diabetes were inevitably shaped by their experiences with the disease. One individual, who described her brother, upon being discharged from hospital, as "still a diabetic," regarded the disease as a transient problem. Another patient associated illness with being sedentary: "When I just lay around, then I get really sick, then I keep going, then I feel active." The rapid progression of the disease was incomprehensible for patients with advanced foot complications. Several amputees reported having little time to process the experience:

> Patient: It really got bad once I got the ulcer on the ankle. I don't know what kind of sickness that was.
>
> Patient: I don't know what happened to my leg; it really got, it got gangrene so I had to have another emergency operation to cut my leg off.

Patients who had witnessed or experienced complications of diabetes first hand expressed a clear appreciation of the seriousness of the disease. However, as providers had suggested, some patients did underestimate the complexity of their own foot problems. One patient was perplexed about how a seemingly minor problem such as a corn had culminated in the loss of his toe: "I don't know, I don't really know what happened because I always see the foot nurse here on the reserve.[004]" Another individual admitted that he had delayed seeking foot care because he believed that his foot "was doing okay [at] that time" and could be managed independently. This individual subsequently had a toe amputation.

4.4D. A PERFECT STORM: A CASE STUDY OF ONE PERSON'S JOURNEY WITH DIABETES

Ella, a 47 year old home care worker, lived in the community with her daughter, son-in-law and four grandchildren. Ella had experienced few significant health problems until the age of 22 when she developed headaches, blurred vision, drowsiness as well as difficulty walking. Ella visited a hospital just outside the community and learned that she had had a heart attack. It was at this time that Ella was informed by a physician that she had diabetes. She recalled the initial advice of the doctor: "He told me to take it easy. Just stay in, like eat less, don't eat fat food or something like that. But I never take junky food." Ella subsequently quit her job.

Ella's foot problems began with what appeared to be a minor injury. In 1987, Ella stepped on a rock while walking barefoot and developed an open wound on her right foot. Initially, Ella tried to take care of the injury herself: "It started to open a little bit but I kept cleaning it up and patching it." Ella eventually sought medical care for her foot. Her foot was first checked by a diabetes nurse and then by her regular physician who treated the wound: "I went to see [my doctor] and he poured some medication there inside. And then he closed it up. Not really closed it up, but put foot patching on there. I still had draining coming out." The foot was slow to heal, she recalled: "I had trouble putting on my shoes because of the foot. It was just like getting larger and larger." As the condition of her foot became worse, Ella sought further help from the diabetes nurse who directed her to a rural hospital [in Town 8] where the wound was debrided. In 2000, Ella was prescribed a pair of custom shoes. She received the shoes within two months and wore them year-round. Ella's foot slowly began to improve.

Recovery of Ella's right foot was interrupted when she again stepped barefoot on a rock in 2001. Ella explained that she often was barefoot while caring for her grandchildren: "Like I have to run to the kids sometimes because nobody's watching them and I was watching them. That's when I stepped on things. But I didn't, I didn't even think about putting my shoes on and running after them. They coulda got hit and run." The injury resulted in another open wound. Ella continued to care of her foot: "I managed to put my foot in the vinegar water and soak it there about half an hour and it cleared up. And I healed it again for a while." Ella again sought treatment from her family doctor. By this time, Ella's custom shoes "were worn already" and she gave them away. Her doctor prescribed a second pair of custom shoes in 2001.

Remarkably, Ella sustained another injury to her right foot. This time Ella sought care immediately: "I stepped on something, then it started bleeding right away. I had to rush myself to the clinic here. And they had to give me some patches and everything." After this third insult, the condition of Ella's right foot became progressively worse. She was admitted several times to a rural hospital [in Town 1] by her family physician for recurrent foot infections. Ella recalled that her last hospital admission for a foot infection had been in September, 2002 for a period of two weeks. Upon discharge, Ella was prescribed medication and instructed on how to clean and soak her foot. Ella returned to the hospital every two weeks for outpatient care, then continued to be monitored occasionally by her family physician at the community health centre.

Ella reported having several falls from slipping on ice in the winter. One fall in January, 2002, resulted in a fracture of her left knee and ankle leaving Ella with residual pain and weakness in her previously healthy leg. By 2002, Ella had not yet received shoes, but did receive a pair of custom orthotics. She wore the orthotics briefly but soon discontinued wearing them due to discomfort.

In April 2003, Ella participated in the Diabetes and Diabetes Complications Screening Study. At the screening, Ella reported having numbness and weakness in her feet as well as foot pain with walking. A thick, hard callus and a dark purple pre-ulcer were observed on her right foot. Monofilament testing of her feet revealed significant loss of protective sensation. Following the screening, Ella's case was directed to the attention of her diabetes nurse who then referred her to another diabetes provider. Ella was subsequently placed on a waiting list to see a foot care nurse. Eventually, she received some foot care from a home care nurse.

By November, 2003, Ella had developed a substantial ulcer on her right foot. Ella described the ulcer: "It used to be so small, now it's really, really large. A little deeper too. . . . I don't know what's the, I don't know what's making a larger hole. . . . And it's smelly. When, something draining out of, it smells, ooh." Ella continued to walk with considerable pain. She had become fearful of falling. She had, by this time, given up waiting for custom shoes. "They said they were going to give me special shoes but they never did," she noted. Ella had decided instead to purchase shoes independently from Wal-Mart. "They're not really comfortable but they're all right," she commented on the shoes she had bought.

In 2003, Ella was seeing two general physicians at the health centre for treatment of the ulcer. Ella described her last doctor's visit: "[The doctor] put some brown stuff on there. I don't even know what it is. And then he said, she said, it might heal on you. But it won't." She had been unable to obtain an appointment with the community foot nurse, but did receive occasional home checkups from a diabetes nurse whom she had developed a deep trust in: "[The nurse] takes my blood pressure, my blood, my sugar, [ ] checks on my sugar. And [uses a] thermometer. [The nurse] knows what I'm going through."

Ella admitted having some difficulty seeing her physicians on a regular basis. She explained: "I couldn't make it yesterday here [at the health centre]. I was going to come and see [my doctor] about [my foot]. I couldn't [go there] because I was short of breath and nobody was home to help me out or anything, so I stayed home." Ella found it difficult to arrange transportation for medical appointments because she did not own a telephone. She usually relied on family members for transportation to the health centre and used the medical transportation service for appointments outside the community. Ella had not been referred to a specialist physician for foot care, but did visit cardiovascular and renal specialists as well as a dietician outside the community regularly. Ella found travel outside the community tedious because of difficulty walking. "I'm getting tired of it already", she noted.

Ella was conscientious about her diet: "I watch what I'm eating, eh. I have to watch real closely." She admitted to skipping meals when traveling out of the community for medical appointments because she often forgot to request meal vouchers on these trips. She was fastidious with the daily care of her foot as instructed by her doctor: "I clean [my feet] all the time. I always have a bath. . . . Take care of my feet, change my socks every day. . . . Change my bandages every day. I change that every day." As Ella described her daily regimen, the toll of caring for the now longstanding ulcer was apparent:

> Sometimes I just want to give up on what's going on with me. I don't know what to think of. . . . I just wish [my foot] could heal, that's all. I don't have a way of healing it any more. It hurts when you try to put a shoe on. I have to put a lot of patching on underneath. That was how the doctor told me to do it. And I put a lot of patching on the bottom of my foot so I can walk real good. It still hurts on the side when it pinches my shoes like this.

After 25 years of living with diabetes, Ella was unable to accept having the disease. She described the unpredictability and pervasive nature of the disease: "I hate it so much. . . . Sometimes I couldn't sleep. I jump up off the bed because I get cramps in both legs, on top of my legs. And if I stay lay, like lay still, I could, I don't know what'll happen to me. . . .Also it affects my kidneys too." Ella recalled experiencing considerable foot pain even at the earliest onset of foot problems: "I had sleepless nights, like almost a month I couldn't sleep. I had terrible times sleeping because my foot starting to ache."

By 2003, Ella's medical problems became more serious. She reported a fainting episode during which she had blacked out. Walking had become increasingly difficult, limited not only by pain but also by shortness of breath. Ella noted, "I can't walk that far, not even half a mile now. I used to be a good walker but not any more." Ella described longstanding problems with her kidneys including at least one emergency hospital admission. She had become resigned to her declining renal status: "My kidneys are going to fail me anyways. They said they're going to put me on dialysis pretty soon." More than the prospect of dialysis itself, Ella most feared the associated risk of amputation: "I might lose my foot. . . . They might have to cut my foot off if it doesn't heal that good, because it's going to go into my foot when I get dialysis. Might turn blue or purple. That's what [the doctor] told me. 'It might affect your foot,' he said. And I'm scared of that. . . . What I'm scared of is losing it. That's what I'm scared of."

Early in 2004, the deteriorating condition of Ella's foot drew the attention of nursing staff. Two nurses at the health centre notified Ella's general physician of her foot status and requested a referral to infectious diseases. In March 2004, Ella was accompanied on a visit to her family physician by her home care nurse who requested a referral to a vascular specialist for the long-standing right foot ulcer. Ella's physician declined the option of referral at both opportunities, and instead provided Ella with some education on footwear.

In March, 2004, Ella attended the Vascular Foot Complications Screening. At this time, she reported having pain at rest as well as numbness in her right foot. She also complained of swelling and cramping in both legs. On observation, Ella's feet were edematous. The callus on her right foot was fissured revealing an ulcer with a foul smelling, seropurulent discharge. Doppler ultrasound ankle pressure tests were inconclusive and suggestive of calcification of vessels. Upon reviewing the results of Ella's foot screen, I faxed an urgent referral to the vascular service in Winnipeg, and contacted her home care nurse to arrange transportation. Ella subsequently visited a vascular specialist in Winnipeg on March 26, 2004. Her ulcer was debrided and she was prescribed antibiotics. She was again prescribed custom shoes.

On a follow-up phone conversation on April 13, 2004, Ella informed me that she had an appointment scheduled with someone to assess her for shoes. She admitted that she had not yet begun taking her antibiotics. In July, 2004, Ella finally did receive a pair of custom shoes. One week later, Ella passed away from complications of diabetes.

4.5 THE STRUCTURAL CONTEXT

4.5A THE SOCIAL AND ECONOMIC ENVIRONMENT

Economic Conditions

Economic Deprivation

Providers acknowledged the adverse conditions in which people in the community lived. Lack of adequate resources in the community was recognized by physicians as a major barrier to the prevention and management of diabetes. Nurses described the extent of economic deprivation within the community:

> Nurse: This community is a community that's suffering. It has poverty, it has poor housing, it has poor leadership.

> Nurse: People do want to work but there's no chance of them working. There's no economic development here, so jobs are only like service type jobs such as these. And there's a few entrepreneurs but not, there's no industry. There's nothing to give people jobs. . . .There is I think a severe lack of education.

Patients offered a glimpse of living conditions within the community that were far from optimal. Access to adequate food was a problem for many residents. One patient noted, "I'm a diabetic, I need something, some energy. I don't have enough for energy all the time, cause I'm not eating good enough to have energy." The lack of availability of healthy food in the community was a concern raised by one resident, "Like, here in town they don't have what I, like what my body wants. I like fresh veggies and stuff like that eh. I go to [Town 1] for that. Like fruits and other stuff. Whatever they give up here is all dried up." Existing food services such as a free school lunch program and homemaker services only addressed the needs of some residents. One patient suggested a "meals on wheels" service could help fill in the gaps for other residents. Another resident identified economic factors as a key barrier to food access:

> Patient: I don't know if it has much to do with diet I guess. Though [people in the community are] instructed how to eat, what to eat, or how much to eat, but still it's an economic factor. . . . Well, a lot of people don't have cars which they can go shopping, pick up what they want to eat or, they don't have

> enough money to buy what they need. Cause people are on welfare, there's hardly enough money to go around for what you need. And being on pension isn't any better. It's only a limited amount of money. That's what makes it difficult. Say like, they suggest you eat vegetables and things like that but, can't keep a vegetable indefinitely, other than potatoes or root vegetable like turnips or beets or carrots. But then again carrots and beets are off our diets because they contain so much potassium. I like parsnips. Parsnip has the most potassium in all the vegetables. Can't eat it.

According to this individual, overcrowded housing in the community contributed to food scarcity as well as other problems:

> Patient: Because it is in a community where it's, say, overpopulated. Relatives and daughters or whoever you have, are crowded in a house due to a housing shortage. It's that what makes it difficult for a person on diabetes. Whatever food they could get or need for their diet is being eaten up by their relatives or sons and daughters. That's a difficulty. . . . And the other problem is smoking. Tell'em not to smoke but still some of them still smoke in a house. Sometimes, some people can't get proper rest because there's too much noise from the relatives, children, or whatever.

One resident in the community reported living with thirteen extended family members in one house. When asked what was the greatest challenge faced in taking care of his health, this individual, who had developed renal complications and chronic foot problems, responded: "What's the hardest thing? I don't have a house. . . . There's always like two or three families in one house. Some houses out here, sometimes four families. It's pretty hard out here."

Residents confirmed that poor socioeconomic conditions were perpetuated by few employment opportunities in the community. "There's not that much work in the community," one resident pointed out. Lack of access to reliable transportation was identified as a key factor in limiting employment options for residents:

> Patient: Some people work on the outside too. Not too many now. See what we lack is a program, transportation. If they had a transportation system where they could transport workers to and from work to help them out. . . . They can't get to work some of them but then, with these old cars, they break down quite often. I think it'd be a good idea too, for the community to own a bus to take the people to work. Maybe that would help curb diabetes a little bit."

Residents also indicated that employment options were limited by inequitable hiring practices in the community, confirming earlier reports of administrators. One resident, who sought seasonal work outside the community, revealed that only members from certain families were eligible for the few jobs available within the community: "A lot of favoritism out here. . . . Like there's, if there's like a job opening, and you know who's going to get it eh. You know like…it's really hard out here. . . . Like the staffing all in here [at the health centre], it's family."

Impact of Economic Conditions

On a collective level, state control of economic resources had fostered a loss of independence and self-worth within the community according to administrators:

> Administrator: Also too, the welfare system, and you know the other past experiences that people have had, has really reduced the people to, like it's created like a child, a dependence. Like who gives you your welfare? The government. The government gives you the house, the government does this and the government does that. The government doesn't do it very well but, you know, like and what do you do, you know, what can you do? There's no, there's nothing around here. So you learn, generation after generation that you just have to breathe and they'll take care of the rest. . . . The system has knocked the life out of, the heart out of the people.
>
> Administrator: …It's like there was always money coming in so [the attitude of people in the community was] 'why should I go out there and work when I'm going to get that money anyways so might as well just stay home.' Like there was nothing out there to motivate them to go out to work and feel good about themselves.

In some cases, government subsidies inadvertently created disincentives for community members to remain healthy:

> Nurse: …There is a lot of false reporting. It's because they get financially funded through Indian Affairs, through the Social Services Department, and the funding is under therapeutic diet, and a lot of people can hardly wait to become diagnosed with diabetes because that means they get more money to live on.
>
> Administrator: …When people were starting to get diagnosed with diabetes, and then social services were starting to increase their diets and what not, and I would hear people say, 'well, if I'm diagnosed as a diabetic, I would get that extra money,' because like they don't have the education or the background to go out there to go out there to look for a job. And so I found that very sad to hear them say that, '[it's] okay if I get sick', without realizing that this is a serious disease that might change their life, but they figured okay, if I got that little bit extra. I'm not even sure how much they got but it was like a little diet increase.

Trapped at a subsistence level of existence, community members were unable to realize their expected potential, providers observed:

> Administrator: My assessment of it all is that this community, and probably that of many others, I've been all over the North as well, is that it's like a depression, a community depression. And if a person takes, well it, you know, I like Maslow's theory, because I think it makes a lot of sense. It explains things simply for me. And that is, like you can't ask people self actualization if they don't have the basic needs met. And we ask them to do self actualizing thing, type activities when there's overcrowding, like economic conditions.

The housing. The, like, you know, what incentive is there? You live in a dust bowl. Your health is influenced by that. There's nothing that can be done or is done.

Nurse: There's so much poverty here, that everybody, you know Maslow's hierarchy eh, they're right at, they're all focused on the bottom of the list. Diabetes doesn't affect them until they do get the complications and then they're in presenting to the nurses and the doctors: 'Make me well, I've got family, I've got to get home, I've got to, I've got to uh you know support them! And to hell with my health, I, you know, just get, make these symptoms better, let them go away. And uh, let me get back to, to my life.

Providers debated the impact of economic hardship on the autonomy of individuals. An Aboriginal administrator examined the spending choices of residents in the context of a history of poverty and deprivation:

Administrator: You see, today there's a need, but there's also a want eh. It's all concentrated on want. They'll buy their kids a hundred dollars pair of socks for example. That's how expensive socks are, yet they don't need 'em. They'll bypass the good stuff like food. They'd rather buy a $200 pair of Nike runners, instead of buying $200 worth of nutritious food. . . . A lot of, a lot of our people suffered poverty, like in [this community]. Specifically [in this community], they suffered a lot of poverty, a lot of hunger. I remember my mom and dad talking about the days they went hungry. They went for days without food because my grandmother was [alone]. People developed the survival skill in that regard. I can live without food but I can't live without this.

Some providers suggested that, despite the economic challenges, residents could still exercise 'intelligent' choices with proper education interventions:

MD Specialist: However what's cheaper? Pop or milk? Vegetables or chips? Smoking. Does anyone hold a gun to your head to smoke? So diet and lifestyle are the major, major factors to control diabetes. I mean insulin and oral hyperglycemics are an adjunct to other management or other modalities. So, it's critical that whenever intervention is done, involve heightened awareness to all these complications. All these issues, diet, lifestyle and so on.

Nurse: I think some people's barriers are their incomes. And then you go to the grocery store and you take a look at the vegetables and fruits, and then you think that they're so much more expensive so they're going to buy chips and pop, thinking it's cheaper. And then it goes back into diet. So we have to, we have to do more teaching, to teach that the fruits and vegetables aren't more pricey, the way that some people think.

An Aboriginal administrator was critical of community members for exploiting the position of dependency: "I think they play a victim role, that's the fact. You know, because there was a lot of dependency created amongst the First Nations people through the welfare system."

In a community with limited infrastructure and few resources, other Aboriginal administrators argued, people simply had fewer choices:

Administrator: There are people here that can actually live on the meager allowance but they go shopping for the cheapest and the bulkiest things to get. They cut on this and that and they actually make their dollars last so they don't starve to death by the end. Not everybody has those talents, and they shouldn't think, well you don't budget. Yeah, there's people that budget, but there's a lot of people that don't know how to budget. Now if somebody gave me a $175 a month to live on. Number one, I would never have my own home probably. I'd have to go live with somebody because I couldn't afford it. I'd probably have to eat their food because if I'm a, if I was a man or a young man, my appetite would have to be curbed a little bit because I wouldn't be able to make, you know, I'd probably be eating about a 100 dollars or more in a couple of weeks if I wanted meat on the table. If it's wintertime, and I, I'm stuck with buying a coat. I might not have enough money to eat. So I would, I'm not sure, I have to make a choice. And it's a hard choice because I'm hungry and I'm cold. . . . So, here's your $175 and I've got a fever, a cold and everything else and I'm going to go and I have to buy my Tylenol now. . . . So, you know, what I might do, is say, you know, I can't do this. And what quality of life do I have. I'm going to take my 175, I'm going to go on a drunk. I'm going to go out and I'm going to have fun for at least one day of the month I'll have, or maybe a couple of days, I'm going to go and have fun. To heck with all of this stuff. So they do.

Administrator: ...Even when I go to the store, like vegetables are so expensive. If you want to buy something with brown or whole wheat bread, it's expensive. Even the whole wheat flour is more expensive than the regular flour. Whole wheat macaroni is twice as much as regular macaroni, you know what I mean. So really I think it has a lot to do with the money issue too. . . . Anything that's healthy for you is expensive. Like, you know, so really if you're living off a $180 dollars a month, what can you, like you know, you break it down that's how many dollars a day that you have to spend on food, hydro, clothing, whatever. Like I don't know how they do it. Like you know what I mean? So usually like something will be bought in bulk, like a bag of flour. That's for bannock, at least you can buy that, like you know.

The inability to live beyond the present was an additional loss incurred by those living in poverty, one administrator observed: "[People expect] that they can get through the day. How can you, how can you, um, how can you live a week down the road? So, and you do things, you do things as you, like as you feel, you know, you sort of don't sit down and plan. Not, some do actually do that which amazes me, but there's a lot that I don't think that do."

Implications

Examining the position of community residents through a wider lens, one nurse questioned society's expectations of people living on social assistance:

Nurse: People should never in this country be living in this way. And how do they expect them to do this any better? How could you expect people? The welfare system has knocked the heart out of the people. It has, it has, it has knocked the heart out of them. And what happens, you know, you get your 100, you're a single person, you get $175 a month to live on. Out of that $175, you're supposed to, you wait for that. What are you going to do? Are you going to sit there and budget your 175? We get mad at them because they don't budget their money and it's all gone in the first part. . . . It's a sad situation because would anybody else, especially those that are pointing fingers, would they be able to do, live in that same kind of condition? I don't think they would do any better.

Providers acknowledged that the health care system did not effectively take into account the living conditions of residents. Several providers noted that the actual eating patterns of people in the community were not routinely considered in the prescription of medications. One physician noted that medications such as insulin were typically prescribed on the assumption that patients were eating three meals a day, when in fact some patients in the community were able to eat only once per day. The prescription of medications in hospital did not account for the actual diet of patients according to one nurse:

> Administrator: ...I've noticed in the hospitals and one of my pet peeves is um you'll send somebody to a physician or to the hospital with a blood sugar of 30. Well 30, like you know, it's been 30 for the last two weeks. Finally get them in there, they hospitalize them, put them on the hospital diet and then put the medication according to what they're eating in the hospital. As soon as they get home, they're back to their regular diet. Like what I wish they'd do is, find out what they're really eating at home, without having to give them, like give them heck. Because when you give them heck they're going to lie about, okay no I'm not eating that. . . . Because and then what they're doing is they'll get their sugars back down to 8 or 10 in the hospital just because they've had no sugar and they've been eating whole wheat. As soon as they get home, it's not going to be that way any more and then the medication that they were, that was ordered for them was according to how their sugars are keeping in the hospital where they're eating hospital food. So that's a big problem all the time.

Expectations within the health care system, one physician observed, were incongruent with the reality of living conditions within the community:

> MD: You know I don't think that a lot of people realize what kind of conditions people live in [this community]. You know they might not have running water sometimes. You know, I actually I have see one person with uh toes with maggots in there. . . .There is just too many things you know whether they have a um damp basement and then fungus growing everywhere. And um you know the hygiene maybe is not, what we expect to see and what actually is happening there, it's quite a different story. Although it is better maybe now than it was 15 years ago.

Social Conditions

Dysfunction

Abuse, prevalent in the community, was a key sign of dysfunction, one Aboriginal administrator observed:

> Administrator: There's another thing that's occurring here too. There's incidences of things that have been happening before, that are not very, they're not really the way traditionally people have treated one another. And that's abuse, like elder abuse. Because the dysfunction is also cause for dysfunction. It's like a plant.

The roots have dysfunctional kind of nodes and stuff like that. The whole plant has sort of got some abnormalities to it and that's the way the reserve is as well, because there's some basic damage done to the roots.

Linking dysfunction to a history of state oppression, another Aboriginal administrator adopted a somewhat paternalistic attitude to the community:

Administrator: Well we had to be very conciliatory talking with people [in the community], you know. Just like, uh, raising a child, just like raising a child. Interesting that their focus behaviour level is of a child. That's what they were concentrated on. . . . Because again, historically with the residential school and the government where people are stuck somewhere and there's a lot of abuse. . . . There has been a lot of oppression, poverty, sexual abuse, emotional abuse. They've been abused left and right. That plays a big part in diabetes.

The community was seen as vulnerable because it remained paradoxically both open and closed to external social forces:

Administrator: We have a door to the outside world more readily available to us. So in that sense, people here can, a lot of people do, communicate. Some people can communicate more with the outside world than they get up North. That probably makes it, now the other side of it is that you also have as good influences are, there's a lot of bad influences. And so we have been subject to a lot of the bad influences of the outside. Such as, I remember when somebody came to the reserve and they wanted to show how gas sniffing, not gas sniffing, glue I think they were using or that spray aerosol stuff. And I remember that, when that started. And it was a guy from the city that came here and introduced it and one lady tried it and died. . . . There's no insulation from the drug scene up here. People like, you know, it's an open door for good, but it's also a bigger door for bad things. . . . [Yet], there's another interesting thing because of the education, it's kind of, it's a funny thing I think, in a way. On the reserve it's a world to itself. I mean it's a kind of insulated world to itself.

Racism and discrimination contributed to a hostile social environment outside the community providers explained:

Nurse: The racism um, even living in [Town 1] and the likes, you see so much of it. The anti-Aboriginal slurs and slander and slang. And there's people that are trying to make a living and do their part and they're being slurred by the views of other people off reserve in the cities, in Winnipeg. And, you can get... it's really disturbing. . . . You know their attitudes about themselves are you know, they don't like going to [Town 1] and dealing with people because they don't trust them. And they know that there's people there saying evil things about them, you know, lazy, no good for nothing Indians and stuff like that. And I've even got relatives that talk that way, you know. And well I don't like it at all.

Administrator: ...People say well, you know, Aboriginals, they go to bingo and all that kind of that razzamatazz. And they do. But, you know, like, me too, think I'd go to bingo if I didn't, if there was nothing else for me. At least, you know, they're socializing. There's um, you're doing, you know, it's fun. They enjoy it. And it seems to me that there's very few things to enjoy, so, you know, like. I was, we were talking to a fellow today and I said, you know like Aboriginal people have a very bad rep. You know, they're, the PR on the reserves is like we're all painted with the same brush and we're all no good Indians and we're all lazy and we're all, all these negative things. And nobody ever sees the people in the home that are just struggling to stay alive. And they don't make the papers. It's the few that really make the, that gives the reputation of what, of what, to the rest of the world, of what, you know, they think then everybody's the same way. That's not true. However, I don't know how people can, I don't know how people can actually do any better.

In the latter comment, an Aboriginal administrator attributed much of the stereotyping of Aboriginal people to the general population's lack of awareness of the reality of living conditions in First Nation communities. Negative societal attitudes had been internalized by residents one nurse observed:

Nurse: ...Perhaps people have adapted the even unconscious perhaps maybe or sometimes conscious attitudes that they're second class citizens. . . . Unfortunately, there's a lot of people on the reserve that have lost that sense of caring about each other because they have been sort of assimilated into this. And in a depression too. I mean it's very difficult to do that in the middle of your own struggle.

A consequence of the blame and neglect of the community by society, this administrator reflected, was that residents had come to feel devalued and alone:

Nurse: I'm only wondering if a lot of the Canadians that are, you know, other Canadians and what they need, if we're looked upon more as a burden like anything else. Sort of like the ulcer of society. . . . You see some just wonderful people that just don't get the time of day from nobody and are just nothing but a statistic and they're nothing but like, you know, a taxes, a tax strain on the rest of the population. You now. They're missing out on some really quality individuals that are just trying to struggle with the meager things they have and nobody gives a damn. And I really honestly think that nobody cares. . . . And I think the worse thing in the whole wide world more than anything else is to think that nobody really gives a damn about you. And if you're walking around in this world and it doesn't matter to anybody else, then how do you feel. . . . One of the things that I am seeing, you know, it's like there's, I think there's a lot of loneliness out there. People are actually lonely.

Recovery of the community was predicated on the improvement of economic conditions, one nurse concluded:

Nurse: . . . It really comes down to health issues in the community. In order for the members of this community to get better, they need employment and housing like I said. Better leadership. They need a lot of help. . . . They need counseling. They need foot, you know proper footwear. . . . It's awful here. Take a look at the roads, and I bet you there's people in Africa that live better than these people do. And those are the things that really need, education, they need, the people need. But I don't think that people are going to get better until they start feeling better about themselves. And that basically starts with getting what they need.

Support

Minimal social support existed in the community according to both providers and patients. One individual living in the community noted, "It's tough like that out here. . . .

Everybody's on their own out here." Another resident observed, ". . . some of them doesn't even care about each other." One nurse observed that only a basic "survival support" was available among the poor. Residents indicated that some informal support was available within and between families. Patients relied on family members for assistance with medical care and other daily activities. In some cases, family members also provided emotional support. One patient with a chronic foot ulcer revealed: "Sometimes too, I would like to give up but I don't. I got my grandchildren, my kids, gotta think about." Occasional peer support was available as one civic minded resident pointed out:

> Resident: We used to visit the people in the hospital. We did that. I'll volunteer for anything. I even volunteer for school or something. . . . People don't understand maybe sometimes what a volunteer is you know. Yeah, when you want to volunteer, go and visit this person, they're going to think that they're going to get paid or something. I know what the volunteer was, and that's what I told 'em before. Volunteer work is not, you don't get paid if you do that. From your heart I said, you help people. And I do that.

However, little support was available to individuals living alone, especially, according to one individual, "the one's that are on welfare." One amputee speculated, "Like if I were to live by myself, I don't think I would have a decent meal." People living alone were perceived to be at risk of isolation and in need of additional support, one resident noted:

> Resident: Maybe more visits or something [are needed] for the people. . . . Even if a person goes to look after the people that are on, the diabetics, like with medications. Like if there was someone just to go check every person, like every day at least, you know. There should be somebody available, there's so many people to you know, that make sure the people take their medicine or something like that. . . . It's hard, like, unless somebody phones them every day, you know, that would be another good idea. Not everybody has a phone.

Patients perceived formal sources of support within the health care system as inadequate. One person pointed out the need for additional support for individuals experiencing stress: "I think [people with diabetes] need somebody that'll really be good to talk to them, to visit them, the sick people. . . . I know those [people] are too busy around here, the health centre, too busy to do that. . . . Because there's a lot of them that have stress eh. I think that'll be good, help them out at times. I think that'll help them out. Maybe wanna try more."

Residents reported that there were limited opportunities in the community to stay active. People in the community spent much of their time watching television or playing bingo one resident indicated. Recreation services in the community were not accessible to all residents according to some participants. Two major families in the community controlled much of the sport activities in the community, residents indicated. These families monopolized both employment opportunities and sports in the community. Organized sports such as sponge hockey and baseball were open only to community members accepted by these families according to one resident. One participant revealed that, until the recent election of a new Chief, access to the community fitness centre was also restricted by these families: "There's not much out here, no. Like the fitness centre, that's just their families that goes in there. . . . They give 'em a tongue lashing if someone wants to go in there like. . . . [People who want to exercise] can't do nothing. If they're not accepted, it's tough luck. . . . [It depends] like if you're making money, then they accept your cheque. Yeah. And how you dress." According to this patient, limited organized recreational opportunities for youth had contributed to other problems in the community including substance abuse: "There is a lot of drugs. . . . I don't do drugs. I betcha some of them, some of our kids do drugs, betcha. . . . Under 25. There's quite a bit around. Like, like adults. . . . Cause they have nothing else to do. There's nothing at all here. All you just have to do is sit and …do whatever, just sit around."

The physical landscape of the community did not support a healthy lifestyle, providers observed. As in other remote rural communities, opportunities to exercise were limited.

The architecture of the community contributed to the isolation of people. One physician pointed out that walking in the community was particularly challenging due to the lack of walking paths and lack of street lights. Providers confirmed that isolation was a problem for many community residents. One resident pointed out: "People are isolated. All the people, they have no transportation, right. Either their family is working and their children are working, like their older children. Like me, all my kids are working, eh, and I can't get nowhere." Patients with disabilities who lived in the community were particularly at a disadvantage according to one administrator:

> Administrator: ...There's nothing wheelchair accessible here. That kind of thing isn't here. People are carried from A to B because there's, when you're talking of mobility, you also have to look at the terrain. Outside the house, it could be like full of mud and bumps and holes and rocks and everything else. And chances of coming out still sitting in your chair, they can't move the chair. Houses are not really necessarily, all of them are not built for wheelchairs. People have become isolated in their homes.

4.5B THE POLITICAL ENVIRONMENT

The Political Arena

Administrators described an adversarial relationship with the federal government by whom they felt unfairly blamed and exploited:

> Administrator: It's a continual fight, because you're dealing with bureaucrats who look at [this community] as a point on the map and they don't see anybody beyond that point on the map. They see us as money gobblers instead of. And we're to blame if it doesn't work out well. . . . People [think] look at that, the Band got so much money, and out of that they get all these freebies. I hear it all the time on the outside. Well, number one, the freebies are bandaids. Number two, a lot of those freebies set bands up to fail because what they do is they say run a hundred dollar program on five cents and if you don't do it, you're not a good manager. You're crooked. You're doing all kinds of stuff. You're incompetent. We want you to run this program. You come up with the money to have a place to work out of. I mean we will give you, you know, like a little, it's a token amount. It's insulting.

Policy makers were viewed as removed from the real issues affecting the community:

> Administrator: I'm very negative of the bureaucrats, and I have very little respect for government double talk and absence of, absence of understanding of human conditions. They're not in those homes. . . . I have very little respect for politicians, and I have very little respect for people that sit in ivory towers and, and look at people, what they're living in and make these kinds of decisions. And then when they're called on it, they skirt around it and people ignore the issues. They ignore it.

Trust emerged as a key issue in state-community relations. One nurse described a lack of "government openness" in the health transfer process. Trust and confidence in the state had been undermined by the legacy of the residential school system according to a non-Aboriginal nurse:

> Nurse: Residential schools messed up a lot of people. I'd never heard about residential schools or the problems till I started working here. But you can see it even in the staff here, um just how messed up, it's really messed up people. And it's also just destroyed the trust. Like it wasn't easy for the likes of myself to get in here. And the only reason that I really got the trust was that I was consistent, and I worked, and I strove hard for the people, and I believed in them. And I advocated for them.

Nurses questioned the federal government's investment in the health of the community:

> Nurse: You know, the bottom line is the dollar. The government is interested in the dollar. It's not interested in the person's health per se. . . . They could not care less about the health of the reserve or of people, of individuals. Individuals are nothing but numbers. That's, that's it. The ones that care about them are the people that are working with them. So the people here are considered nothing but a number.

> Nurse: Medical Services isn't willing to finance [an increase in foot care services] because they know it's going to cost them an arm and a leg

Financing of the Health Care System

Allocation of Funding: The Role of Governments

Health administrators and providers were critical of federal funding of community health programs. Funding levels had not accounted for the specific needs of the community, one administrator pointed out:

> Administrator: I actually think that what it should be is like having needs-based funding rather than formula-based funding. And I wish they would stop comparing us to provincial and other types of health populations. . . . Basically our health needs are not the same, they're quite a bit different or more. I think they're more severe than the general population in a lot of ways. And there, and it's only based on a formula. Somebody comes up with a formula. The funding that I got for this program as a contribution agreement just as sort of a start-up thing, it was supposed to be, like it was done by some formula. But it's just trial and error. It's like, well, we'll start off, this could be about the amount they might use, that kind of a thing. And we'll use this kind of formula, which is probably based on maybe a population, some other, another population in the area. Now, what they're saying is that this is the funding that you're going to get to do all of this stuff. No changes. That's called dirty pool.

Providers found themselves straddling the gap between formula-based funding and the health needs of the community:

Nurse: The federal government started up the Home and Community Care Program which the community needed. But dinky amounts of money, that you know you could just barely pay the wages with. Same with the Community Diabetes Worker. You know over 2/3 of the funding, and in order to get somebody that's half decent, to, to stay in the program and you know, and get the training and do the work, it costs. You know most of it goes into wages. And, we're scraping, scraping the remainder of it into clinics and workshops and group things.

Administrator: I think they gave us 48,000 dollars for medical services. For a facility. . . . [For] home care. And they said, well that, 48,000 dollars will get you about two rooms. That should be enough to run your program. . . .That is a travesty. . . . The province has 2%, this is what we found 2% need this service. So reserves are now going to get the re-service. They have 17% of people with this problem, but they're going to go on the funding of the 2%. Okay, if I don't do my job and meet the 17% basically, if they care at all, but I guess that would be, then it appears that I'm, like what am I doing? I have 15% of the population that aren't getting anything. Well that's exactly what's happening in foot care. And, and so 15% are getting diddly squat, because I can't do more than that. I don't have the man hours, I don't have the resources. What am I going to do?

Minimal increases in funding did not support the growth of programs in the community according to administrators. One administrator described the consequence of capped contribution funding of medical transportation:

Administrator: Funding for transportation has not increased for six years. We are now really starting to feel the crunch of a tight budget. The first service we've had to cut was gas vouchers. . . . Right now [the transportation service] is not that efficient. It's like I can honestly see that because of the underfunding, and we have to replace those vans because they're like at that stage where they're not safe because they're older and they're constantly on the road.

Administrators adopted various strategies to keep programs afloat. In some cases, managers agreed to share funds by "piggybacking" on programs with surplus funds in order to meet the needs of the community. Administrators facing continued deficits had to appeal to local and federal governments for additional funding to maintain program operations. Past efforts by the community health administration to lobby governments for increased preventive care and foot care services proved unsuccessful:

Nurse: The waiting list [for foot care] was up to 80 when we last submitted a proposal to FNIHB to increase services, but we never heard back. FNIHB then renewed [the foot care] contract at the same level as before.

Administrator: Home Care had tried to fundraise for foot care services like a shoe account so people could have decent shoes. We wrote proposals for this to Chief and Council. But I'm not sure they even got it. I suspect it was blocked.

Administrator: We submitted a proposal to FNIHB to increase services for preventive care in August 2003. This is still in negotiations. FNIHB is asking for more information.

Consequently, foot care was occasionally provided within community health programs in an unofficial capacity, health administrators admitted, in order to meet the needs of the community:

> Administrator: [Community nurses] can do an assessment but we're not funded to do foot assessments. The only time they have at this point is a bunch of clients, like they'll go that extra mile to do a foot assessment because [patients] are already running into other problems…
>
> Administrator: Recently, some home care nurses received foot care training. This was funded through home care's budget which is not really allowed by FNIHB, but the training was needed and this was the only way Home Care could get it.

There was little consensus between decision-makers at all levels of government on how health funds should be allocated in the community. Providers regarded federal funding priorities as restrictive and short-sighted. One nurse indicated that diabetes treatment, for example, was difficult to provide within federally funded programs that mandated education and prevention.

Shifts in the key players impacted the decision-making process:

> Nurse: …You get a lot of the political powers you know in the federal government, and they're changing all the time and, so there's no consistency, and there's no trust.
>
> Administrator: For the past two years we've been in a deficit because of, I guess, leadership changes and that. . . . So what happened is a lot of the funding, our proposals that we had set had to be put aside, and then we had to work within the limited budget that we are in right now.

Health providers and administrators played an increasingly smaller role in the allocation of health funds as local government assumed greater control of health funds. One administrator noted that funding for programs had become more difficult to secure: "Now everything has to have prior approval. And it has to go through several people. . . . . Before, I would do the paperwork. This is what needs to be done and this is why. Now we still need the paperwork and prior approval also. It's good in some ways because there's always a paper trail if I have complaints, but there's too many hurdles.

Another administrator reported that surplus funds set aside for foot care and other services by program managers in 2004 were redirected by the community leadership:

Administrator: All the transfer programs together had a surplus.... Home Care had a surplus of ... We were saving this money for services that were really needed. You see any surplus under the Transfer Agreement can be carried over from past years. But surpluses under the Consolidated Contribution Agreement cannot be carried over, the money has to be used within that year. That's why Home Care was trying to use their surplus for more foot services. . . . The new Chief and Council took over all the funds soon after they came into power, and then we were no longer able to track spending after that.

Transfer of Health Services

Control of foot care in the community remained contentious. Transfer of foot care services was indicative of a larger federal strategy, nurses argued, to shift fiscal responsibility of health services to the community:

Nurse: . . . [FNIHB] wants to put the foot care nurse under the Home and Community Care Program, and that way they would eliminate the funding for, for this foot care nursing and it would come out of the funds of Home and Community Care, which are just as pitiful as, as the Community Diabetes Worker funds. . . . You know they're trying to cut back the services, health services. And I know, whether they're trying to cut back and get out of it or what? Um... it's definitely happening. You never know from month to month what medications are, are on the card for, that are available to people.

Nurse: Medical Services wants to get rid of the foot care. They want us to take it. They want to transfer it. As it is now, they give us two days a month. . . . Now a foot care nurse, they wanted to give us I think 11,000 dollars to run that program. And I said, I'm going to refuse. I would never take it if I, if I had a choice because what are you going to get for 11,000 dollars when you need somebody full time. . . . And so what they want to do is dump it into Home Care. Home care could pick up the difference. Home care is supposed to be picking up the difference of a lot of things. So they don't have, they don't have a fully, they don't have the money to run it like it should. So what they want to do is dump them on the reserve and the reserve has to scramble and that's the same principle, here's a 1,000 dollar need, and, you know, there's a 100 dollars to operate but we're giving you 5 dollars. How come you can't meet the need? How come you meet the need? Like there's not even a question about that. . . . Like with Medical Services, non-insured health benefits as much as they say that they're there for the people, it's a bunch of garbage as far as I'm concerned. They've cut down, and this is a typical strategy, they cut down, they cut down and cut down and cut down. And then what they're doing now is they're saying they want to transfer that program. So they cut it down into the bare minimum so that you have hardly anything to transfer and they'll say, well you could manage it now.

Nurses alleged that because the federal government scaled down health programs prior to transfer, programs inherited by the community were barely operational:

Nurse: We're doing only bare minimum. We're a small, small program. The idea is that we're mature, we're supposed to transit. Well I'm not, I just hope we don't transfer until, when they define maturity and it's my concept of home care. I want to make sure that their concept of home care is close to my concept of home care which is like the adult day meals program, like all of the supportive services. That should be a home care program. I think what they're trying to do is now that they're saying well you've got a home care program, they just wipe their hands and well what's the matter with you, you've got your program.

> How come you're so incompetent that you can't run it or, you know, like you're not doing your job. We need to audit you. We're coming up with our fourth audit this year.

Transfer of health services represented a tradeoff between control and sufficient funding according to administrators.

In the past, community health administrators had been a key part of health transfer negotiations with FNIHB. Unwilling to compromise expectations of increased funding, administrators and providers had declined past federal proposals for transfer of foot care services. More recently, however, health care staff were excluded from the transfer negotiations involving the very programs they administered and delivered. Many were stunned by the transfer agreement accepted by the leadership:

> Administrator: We used to review every new agreement with FNIHB with a fine tooth comb and compare it with the previous agreement for changes. Then I would complain if we weren't happy with the changes. When the new Chief and Council took over they signed new agreements and reviewed them afterwards. They agreed to new programs such as support services for adult day care without receiving more funding. When I found this out, I was furious. I told them I couldn't believe what they had done without consulting us.

> Administrator: ...There wasn't enough planning in place. [The leadership] figured, okay, we'll implement this without consulting the, let's say for my program, they didn't consult me when they accepted the agreements for, let's say, for example, meals, that kind of thing. Without considering the extra dollars that had to come into play if we're going to offer meals now for clients during the summer. . . . They kind of dropped it into my lap with no funding in place yet. . . . It's at that level where I'm kinda stuck between a rock and a hard place, where I know what needs to be done. [The leadership are] the ones that sign those agreements. So there's only so much I can do.

Policy on Foot Care: Systems of Remuneration

Physician remuneration structures impacted practice styles and the quality of care. The caseloads of primary care physicians working in the community varied according to location of practice and/or type of physician funding. Physicians interviewed from two hospital groups discussed their caseloads. Physicians from Group 1 were funded on a fee-for-service basis and reported seeing an average range of 30 to 50 patients per clinic. In contrast, Group 2 physicians were on salary and reported seeing 18 to 25 patients on average per clinic. Care practices differed between physicians from the two groups. Salaried physicians from Group 2 were assisted by a regular nurse during community clinics. For this group, the nurse served as a "steady link" between different physicians enabling greater continuity of care for patients in the community. Non-salaried physicians did not opt for additional nursing support. These physicians indicated that limited work space at the community health centre was a deterrent to increasing staff. A physician from Group 2 described the impact of funding on patient care:

> MD: I must say that it is a privileged situation because you know I'm not working fee-for-service, because if I would be, I'm not sure how it would be. Like I think you know you need the time to spend with the people, and if you were fee for service, like I'm not sure you know how you do that. It's harder. It's definitely harder. So that's why I'm saying that's you know it's a privilege and , you know I mean I have worked fee-for-service elsewhere and I know you're not just able to spend all the time that you would want to.

The extra time afforded by a salaried position facilitated better trust and communication with Aboriginal patients according to this physician.

Remuneration of primary care practitioners was an important consideration in reforming diabetes care according to physician specialists. Specialists maintained that there had to be financial incentive for practitioners to improve competency levels. One specialist suggested that salaried physicians were more inclined to improving practice standards than physicians funded on a fee-for-service basis: "You can train a nurse to do [complete vascular foot assessments] that's salaried, that's fine. If you get a doctor to do it, he must be remunerated or he won't do it. I mean that's life. You see if the doctor is salaried, you know then he will do it, because he doesn't have that many patients to see right? No, but I think the bottom line is education for the first line facets, nurses and for the family docs."

Foot care nurse services in the community were administered by FNIHB on a contractual basis. Funding for foot care was determined by a tender bid process by nurses based on estimated need. Nurses providing foot care had negotiated a per diem payment arrangement. Renewal of funding for foot care services was determined according to previous care provided which, one nurse admitted, was not a reliable indicator of the actual demand for care:

> Nurse: ...Like First Nations Inuit Health Branch, they're the ones that actually decide how much they're going to pay. . . . It's based on last year, how many people I've seen last year. They'd look at the list of when I sent in my invoices they seen how many people. They average that out through the whole year and then they divide that. . . . But if they look at the schedule, I mean if they look at my, the amount of people I've seen from this year, if I see less this year than I did the year before, they're not going to provide that funding. And it's not because there isn't a demand for it.

Access to private foot care was hindered by cost and funding restrictions, according to providers, leaving community residents with few alternative options for basic foot care:

> Diabetes Provider: I tried to send a few people down to [a podiatrist] who is a specialist from Winnipeg. . . . And this just happened within the month to sort of alleviate this, this waiting list that we've got, and it ended up they we're going to get charged for their foot care services and Medical Services wouldn't touch it. And yet these are people that are eligible for foot care. They're on the waiting list; they need foot care services but Medical Services, and you know we've got our foot care nurse maxed to the max and they're saying well they've got to use the foot care services. . . . There are some private foot clinics in [Town L01]. Foot care at these clinics could be covered, but I'm not sure what criteria is needed. We haven't gone this route because it would involve a lot of paperwork.

> Diabetes Provider: I don't know who to contact for them to get more foot care, more foot care time because I tried booking them [a private foot care centre] but at the time they never told me that there's a 40 or 45 dollar fee that you have to pay right away.

Residents were eligible for select podiatry services contracted by Social Services or by the federal government within surrounding hospitals. Nurses indicated, however, that some providers were discouraged from continuing to offer services to community residents due to long delays in reimbursement from government. In addition, nurses were deterred from referring patients to foot care providers outside the community by a tedious application process. One nurse, who admittedly referred only one patient per year to podiatrists outside the community, explained:

> Nurse: There's a mile of paperwork to uh, and usually that's where I would hear from them is they'd need a doctor's prescription. These poor doctors, they must be God or something because you got to go chasing after them for you know any little thing they've got to have a signature. On some items, on some

procedures you have to have two doctors, and you know both the doctors sign two separate, you know prescription slips plus the form, the FNIHB form. It's just ludicrous.

Policy on Footwear

Providers observed that government funding policies did not support upstream diabetes care. Both nurses and physicians pointed out that changes in federal policy on the funding of footwear had effectively decreased patient access to preventive foot care. In 1985, FNIHB modified the criteria for subsidized footwear for diabetic patients. After this time, nurses reported, only custom shoes, custom orthotics and prosthetics were subsidized. Funding for other types of shoes such as box toe, extra depth shoes was also discontinued. Funding for orthotics required authorization from several levels including the Band Council, a physician, and sometimes also from a specialist, according to one physician. A nurse described the process of acquiring shoes for diabetes patients in the community under the current federal footwear policy:

Nurse: Referrals have to be written exactly the way FNIHB wants. For example the diagnosis has to be on there. They're often not filled out properly and sent back to me. . . . If approved, people can get their shoes within a month. But many people can't get shoes. The appeal process then takes months and involves a lot of paperwork. . . . Usually applications for box toe, extra depth shoes are denied because they are not considered medical shoes. The problem is that there is a grey area as to what people are actually eligible for. The community seems to think they can get whatever shoes they want. Some of the doctors know what's eligible, some don't. But I can send in the same prescription twice – say for a flat foot, and one will get funded and one won't.

Policy changes complicated access to other essential medical supplies according to one nurse:

Nurse: You know up until about three or four years ago, oxygen was provided and people got it and, and we were careful. You know I tried to be as careful as I could with it and somebody stepped in. Same with wheelchairs. I used to be able to get wheelchairs, like that . And now, this would be about '96, '97 [FNIHB] decided, well we've got to you know, and the next thing you know I have to send all this paperwork in to FNIHB…

One physician questioned the intent of federal footwear policy:

MD: Orthotics are a pain in the ass. …Well ask [the nurse] who does the Indian Affairs form. I think, they probably threw up the roadblocks because there's probably too many being ordered. …Sometimes, if somebody requests it, I'll write them a prescription for orthotics, and perhaps too many people were going for orthotics and perhaps they weren't being used. Somebody made a survey of how not all these people

> were actually using the service so let's make the process a little more difficult for us etcetera. So only the ones who are really persistent get through.

Another physician observed that footwear policy appeared to vary between First Nation communities. The number of pairs of shoes patients were eligible for, for example, differed between communities, this physician noted. Patients in this community were eligible for only one pair of footwear per year a nurse confirmed.

Lack of access to appropriate footwear was identified by most providers as a significant barrier to effective management of foot complications. Physicians reported that few patients in the community had access to custom footwear due to insufficient financial support from local and federal governments. Alternate financial support for footwear was difficult to secure from local government as one nurse explained:

> Nurse: The Band has sometimes provided footwear for elders. We had one elder who was not eligible for shoes on initial assessment. So we faxed it to the Chief, and we had the supplier invoice the Band, but nothing happened. So I had to explain to Chief and Council what needed to be done. I refaxed the invoice, and eventually had to walk it over and they agreed to fund it. But that was an exception because they were under third party management.

Most patients, physicians noted, were unable to access or afford proper shoes and often resorted to buying cheaper shoes from discount stores. Those patients who were deemed eligible for footwear coverage had to be quite persistent in order to receive footwear. One physician noted that the inability of patients to obtain proper shoes due to restrictive funding policies further compromised the difficult process of managing a diabetic foot ulcer:

> MD: ...You know even if I heal an ulcer, which I'm really proud of, you know, [governments] say well they won't do this and they won't do that. I mean there is only a limit they can, I think the only time you are actually allowed to have footwear made to measure is if you already have an amputation. I mean you can send [patients] to podiatry but that's all on their own. I don't think there's any coverage for the First Nations, you know like from the Band or anything like that. And you know, so how do you persuade somebody to spend $300 on footwear?

As a consequence of restrictive footwear policy, some physicians admitted that they were discouraged from prescribing footwear_or referring patients for podiatry care.

Jurisdiction

Organizational Challenges

Health providers in the community were funded by different levels of government resulting in a dual health administration. Separate systems of funding in the community had resulted in distinct organizational structures with limited exchange of health information according to one physician:

> MD: I guess the other thing that is not probably helpful [is] that the reserves are financially supported by the federal government right. While the physicians and uh mostly the physicians, I mean they are staffed by the provincial government. And sometimes we don't get any data. For example if there is an outbreak, we don't get necessarily any data because it goes to federal government, or there you know there is not such a great communication between provincial and federal government. So this two, you know two tier system or whatever you want to call it, you know sometimes causes problems too.

Employment of staff at the health centre by different levels of government for variable terms added some 'instability' to the workplace, one nurse suggested:

> Nurse: Basically the foot care nurse is signed up under contract by Medical Services. So she doesn't even really work under the umbrella of the health centre. She's, she's more or less employed by FNIHB. Now these guys, for example, her contract was up yesterday with FNIHB. We don't know for sure if she's going to get contracted again for another subsequent, we might have to start up with a whole new person. And there we go. We got to start, we got to build up the trust in the people again. There's no consistency.

Ensuring accountability of contract staff was a challenge one administrator explained: "…[The staff member is] contracted out to FNIHB. Their guidelines are far different from ours. And that's their contract with FNIHB. She might go back and complain to them eh, and then we won't have a [health provider]. See that's the dilemma again. Unless we get her on our side, and say, hey, this is what, this is our idea, you think that might work."

Gaps in Care

Jurisdictional divisions also complicated access to some services such as diabetes education resources according to providers:

> Nurse: The diabetes education resource is set up by the province of Manitoba, and... they have, there's, we've tried to get them to come up here and provide service, and they just, they won't even touch that one. This is federal territory and um provincial just does not go into that territory.

> MD: One thing that does not perhaps work as well is diabetic education. There is that problem with this, you know that they don't come to the reserves because it is federal. You know, the ER is provincial. So there is some problem with that.

The intersection between provincial and federal funding systems was particularly conspicuous in the scope of medical transportation services. Medical transportation for provincial programs was restricted. One administrator explained the challenges this created for residents in accessing high demand services such as counseling: "Counseling is another thing that's increased. There's more and more people going out, going to different areas for counseling. . . . Funding was coming through FNIHB and because there's counselors being paid to do that service, we weren't allowed to go off the reserve to seek that service if the FNIHB [counselors] were overbooked [023]." In some cases, residents were caught between the two funding systems:

> Administrator: People on social assistance are on assistance with the Province, so [for medical transportation provided to this group] we bill FNIHB and they bill the province. But these are the first people we bump if we need to. They are told this ahead of time. We will issue them gas vouchers if we have to bump them, but it's a hassle for them especially in the wintertime. . . .We had a case where someone was living off reserve on social assistance. FNIHB won't cover transportation for this person because he is on social assistance.

Lack of clarity and consensus about jurisdictional boundaries resulted in gaps in care. Transportation for foot care in the community was temporarily discontinued in 2001 because foot care was considered a "separate entity" from the community's health programs and deemed the responsibility of FNIHB. Transportation for foot care was part of the community's original contract for foot care with FNIHB, according to one nurse. Although foot care transportation was restored in 2003, jurisdiction for foot care remained unresolved according to one administrator: "We will transport people to see the foot nurse locally. We had some problems. There was confusion as to what was covered. We met with all the nurses to set priorities and seek clarification. We found services to the foot nurse are not covered as part of our budget, but are a part of FNIHB's budget. So we are now doing it as a courtesy. There is ongoing negotiation about this."

Providers viewed the problem of insufficient resources for diabetes care as outside their scope of practice. One foot care provider indicated that addressing the unmet demand for foot care was the responsibility of the community health authority:

> Foot Care Provider: ...That's not part of my department. That's up to the people that are working in the clinic here. Like it will be up to [nurses and nurse administrators at the health centre]. I don't know who, but it would be someone. . . . It would have to be, it would have to be the centre that sends in the waiting list and say well this is what the waiting list is. And that was, that would actually be, probably be a good idea at the end of the year. Like coming at the end of this year, December, if they look at it and said, this is how many people that have been waiting to see the foot care nurse, is it possible that we could get more foot care days. . . . [Medical Services has] control over how much money they're going to pay for the foot care, for the amount of people that are seen. So, unless the clinic can show that there's more people that need to be seen, I think it's the only way that it can change.

A physician specialist believed that the responsibility for improving resources for diabetes care rested with both patients and governments:

> MD Specialist: I'll do my part. And if the Manitoba Government or the Saskatchewan Government or Alberta Government wants to intervene, great. But I stopped doing charity work for the provincial government. I've stopped being a babysitter for the patients in the communities. If they don't have the resources, this is what you need to do. Come back and see me when you have the resources. Otherwise, I'll see you again but there's nothing I can do for you. . . . There's only so much I can do. I mean I can give interventions. I can give advice, but if the advice isn't acted upon, what am I doing?

Lack of adequate resources for foot care in First Nation communities, according to physicians, was ultimately a reflection of the lack of will of both local and federal governments:

> MD Specialist: The administration of the communities, Manitoba Health. There's lip service but there's no actual commitment to make anything happen. The Manitoba Diabetes Strategy is a brilliant document. Has it been implemented? ...What it comes down to is, is the community prepared to spend money to have someone go out and clip toenails and file calluses? Most communities are not.

4.6 SUMMARY OF RESULTS

4.6A THE PROBLEM OF DIABETES-RELATED FOOT COMPLICATIONS AND AMPUTATIONS

Severity of Disease

Caseloads of physicians and nurses and the experiences of people living with complications of diabetes reveal a disease well established and largely uncontrolled in the community. Reports of an estimated six-fold increase in cases of diabetes in the community over the past twenty years confirmed the increasing prevalence of the disease.

The severity of the disease in the community was evidenced by reports of the young onset of diabetes and diabetes complications, high comorbidity and the rapid progression of foot complications. People in the community were developing diabetes at a younger age (25 to 35 years), and were especially vulnerable to cardiovascular disease and renal complications. Diabetes foot complications progressed extremely rapidly in many individuals leaving little time for people to respond. Foot lesions complicated by infection usually culminated in multiple, emergent amputations.

Impact of Illness and Disease

Complications of diabetes not only challenged the capacity of the health system, but also altered the lives of the people and the fabric of society in the community. The physical and emotional burden of living with chronic foot lesions is evident in the stories of people in the community. The experience of foot complications and amputations for these people was characterized by disability and loss. Disability associated with advanced foot complications typically included multisystem health problems, loss of energy, mobility and in some cases the use of senses. People with foot ulcers typically endured a prolonged course of recurrent infection and frequent hospitalization. The anxiety of managing a non-healing ulcer, for some, was overwhelming. In the case of Ella, fear of amputation eclipsed even the prospect of renal failure, undermining the quality of her final years. For many individuals, the physical ordeal of a chronic foot ulcer ended only with the rapid onset of gangrene and emergent amputation. Amputation brought few benefits for its survivors. Some people acknowledged considerable pain relief after surgery. Many, however, had lost the ability to walk and live independently. People of all ages who had sustained amputations described the inability to do what they had once enjoyed. The loss of independence and place in the community proved far more disabling for these individuals than was the physical losses they experienced.

The health system lacked the resources and the capacity to effectively manage diabetes at epidemic levels. Providers were overwhelmed by the early onset of complications and the high demand for care. Some were frustrated with their inability to effectively control progression of the disease. Many providers expressed pessimism about the prognosis of people in the community with advanced foot lesions. These attitudes were shared by many people with diabetes in the community who developed a sense of fatalism and resignation towards their health.

Complications of diabetes exacted a high human cost in the community. People reported amputation to be a common occurrence among several family members. The loss of multiple generations of family members from diabetes complications transformed the lives of people and altered the social, cultural and economic fabric of the society.

4.6B FACTORS CONTRIBUTING TO THE DEVELOPMENT OF FOOT COMPLICATIONS AND AMPUTATIONS

The collective data gathered from documents, interviews with key informants, and interactions with stakeholders at workshops, screening clinics and forum meetings reveal a large array of factors associated with the problem of diabetes foot complications and amputations. These contributing factors may be grouped into three main categories: (1) individual level factors, (2) health systems level factors, and (3) broad determinants of health summarized in Figures 1, 2, 3 and 4.

Individual level factors are characteristics of individuals that may be proximally linked to a health problem. These factors include genetic susceptibility, personal lifestyles and behaviours. Lifestyle may be defined as "a complex of related practices and behavioural patterns in a person or group, maintained with some consistency over time" (Green & Kreuter, 1999). The behaviour, actions and practices of individuals are common targets of health education and health promotion. At the individual level (Figure 2), participants identified risk factors for diabetes and diabetes complications – genetic predisposition as well as lifestyle and health behaviours – as playing a prominent role in the development of diabetes and diabetes complications. The knowledge, attitudes, beliefs and values that motivated the health behaviour and practices of patients, providers and administrators were also identified at this level. What providers did in their practice of delivering diabetes care and foot care, as well as how patients interacted with the health care system and managed their own feet also influenced foot health outcomes.

Structural level factors are conditions in the environment outside the realm of the individual that shape the behaviour and actions of individuals. Structural level factors include both health systems factors occurring at an administrative level, as well as the broad determinants of health at a more distal level. *Health systems factors* are the organizational capacity (availability and coordination of resources) and the operations (delivery of services) of health care systems. The organization and coordination of health services, the availability of resources, the accessibility of health services and the work conditions providers experienced were identified as factors in the health care environment influencing foot care in the community (Figure 3).

The *broad determinants* of health are the social, economic and political forces than can have powerful effects on the health of populations. Health-related behaviour may be viewed as "socially conditioned, culturally imbedded, economically constrained patterns of living" (Green & Kreuter, 1999). Health policy, funding arrangements and socioeconomic conditions were identified as key determinants impacting foot health outcomes in the community (Figure 4).

Establishing priorities among the factors identified in order to determine goals for intervention is ultimately the task of the community health authority and community leaders. The factors associated with diabetes foot complications and amputations, summarized in Figures 2, 3, and 4 were all deemed important by stakeholders in this study. In the final analysis of the data, significance of contributing factors was established using the dimensions of importance and changeability. Criteria for importance were based on the frequency with which the concepts surrounding a factor emerged in narratives, and how clearly and strongly the concepts related to foot health outcomes. The criterion of changeability was based on how susceptible a factor was to change and included practical considerations of time and feasibility of change (Green & Kreuter, 1999).

Factors operating at the level of health systems were ranked more highly than other factors. These factors were deemed to be important because change at a systems level was recognized as having broader, more powerful effects than change at an individual level. Change at a systems level is also more feasible in the short term than the greater task of changing social, economic and political conditions. The factors that were determined to be most significantly associated with poor foot health outcomes are identified in Figure 1 with as asterisk.

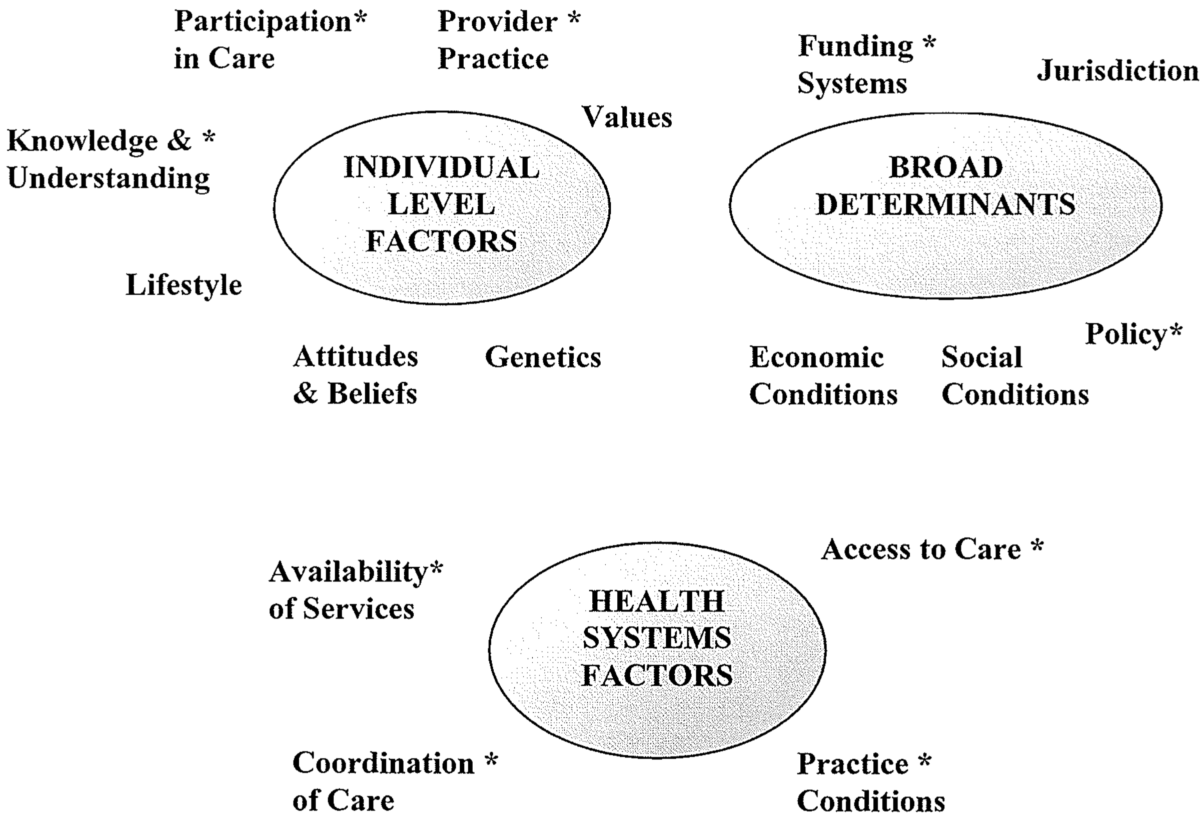


Figure 1
Factors associated with diabetes-related foot complications and amputations

*** significant factors**

Values of People

- Independence
- Self-sufficiency

Genetics

- Genetic predisposition to diabetes

Lifestyle

- Diet high in sugar and fat
- Insufficient exercise
- Smoking common practice

INDIVIDUAL LEVEL FACTORS

Attitudes & Beliefs of Providers

- Primary prevention of diabetes is a higher priority than secondary prevention
- Foot assessment is a lesser priority than managing acute problems
- Effectiveness of regular foot assessment is questionable
- Foot care is a lesser priority within mandate of prevention than pt education
- Maintaining regular standards of diabetes care is unrealistic in community
- Diabetes complications of First Nation patients should be treated aggressively
- Foot complications in elderly people should be treated conservatively
- Patients have low expectations of care and are not receptive to standard care
- Patients are not compliant
- Patients lack will to help themselves
- Resignation to poor health outcomes
- Management of diabetes is largely an individual responsibility

Practice of Providers

- Manage large caseloads
- See a diverse case mix with a high proportion of advanced/end stage foot problems
- Do not adhere to diabetes practice guidelines
- Perform incomplete diabetes assessments
- Do not provide routine screening
- Do not provide regular/complete foot exams
- Delay treatment of foot problems
- Refer few patients to specialists
- Refer patients at late stage
- Do not flag urgent cases
- Focus on management of acute problems
- Focus on patient education

Attitudes & Beliefs of People

- Family doctors should be seen only for serious illness
- Low expectations of health care system
- Resignation to poor health outcomes
- Management of diabetes is largely an individual responsibility

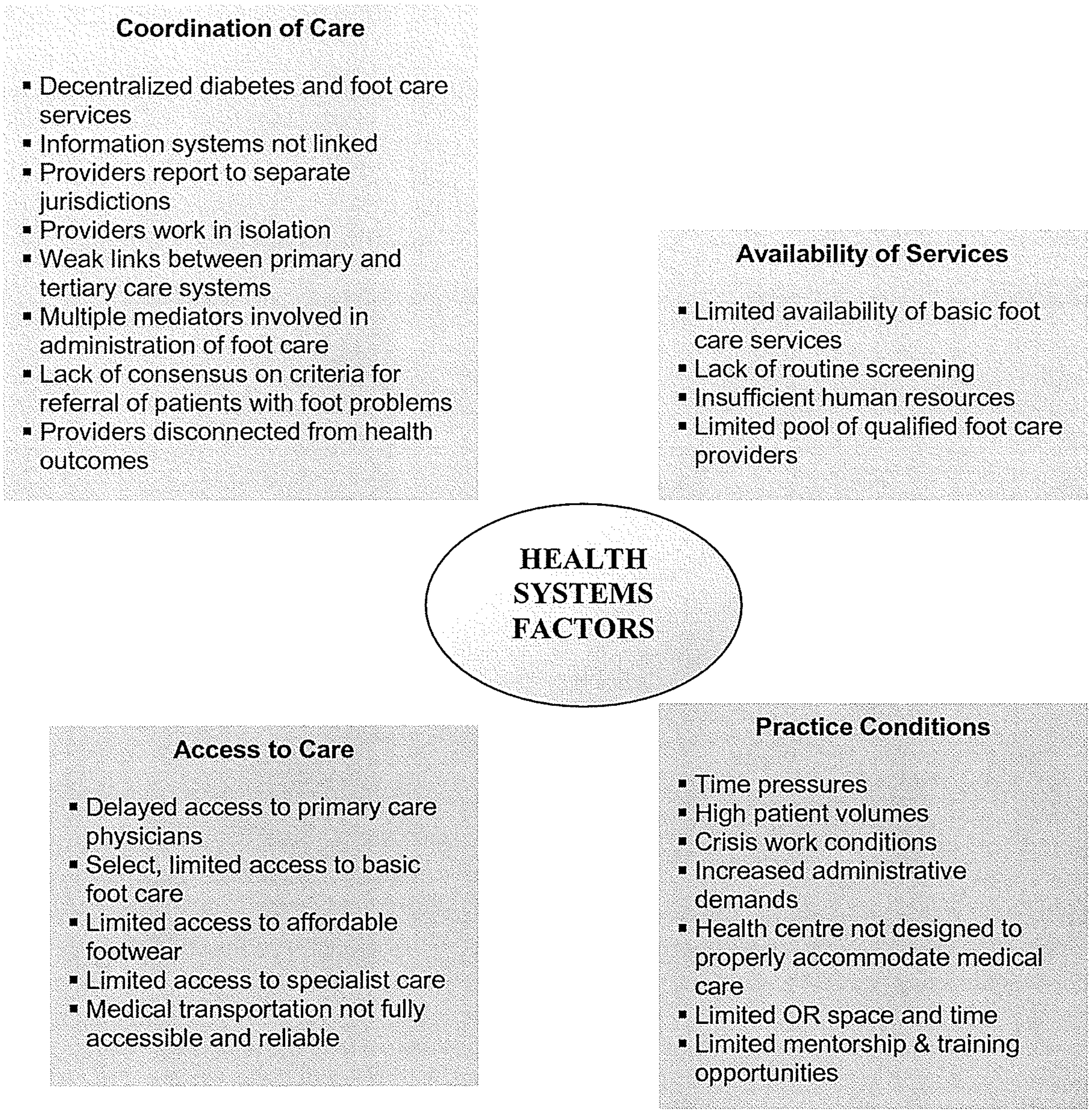
Knowledge

- People lack sufficient knowledge about diabetes and diabetes management
- People do not appreciate seriousness of diabetes
- People lack awareness of body
- People demonstrate a complex understanding of diabetes
- Providers lack sufficient knowledge about foot care and available resources
- Providers do not appreciate extent of demand for foot care

Participation of People in Care

- Do not seek regular primary care in community
- Few seek early or regular foot care
- Seek foot care in hospital system
- Few use medical transportation to visit specialists
- Do not follow up with appointments
- Proactive role with specialist care
- Diligent with self-care

Figure 2
Individual level factors associated with diabetes-related foot complications and amputations



Coordination of Care

- Decentralized diabetes and foot care services
- Information systems not linked
- Providers report to separate jurisdictions
- Providers work in isolation
- Weak links between primary and tertiary care systems
- Multiple mediators involved in administration of foot care
- Lack of consensus on criteria for referral of patients with foot problems
- Providers disconnected from health outcomes

Availability of Services

- Limited availability of basic foot care services
- Lack of routine screening
- Insufficient human resources
- Limited pool of qualified foot care providers

HEALTH SYSTEMS FACTORS

Access to Care

- Delayed access to primary care physicians
- Select, limited access to basic foot care
- Limited access to affordable footwear
- Limited access to specialist care
- Medical transportation not fully accessible and reliable

Practice Conditions

- Time pressures
- High patient volumes
- Crisis work conditions
- Increased administrative demands
- Health centre not designed to properly accommodate medical care
- Limited OR space and time
- Limited mentorship & training opportunities

Figure 3
Health systems factors associated with diabetes-related foot complications and amputations.

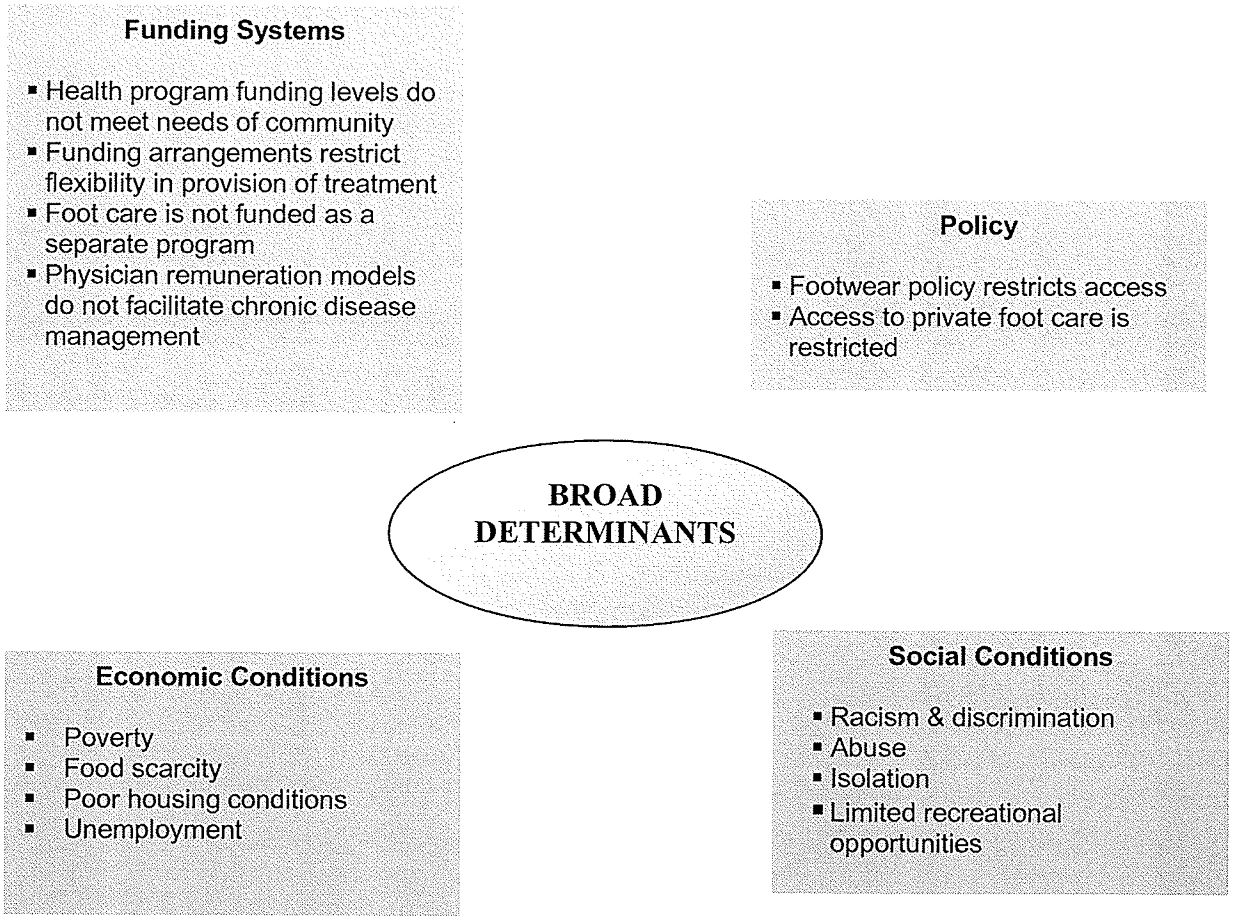


Figure 4
Broad determinants of diabetes-related foot complications and amputations.

CHAPTER FIVE

DISCUSSION

5.1 SITUATING THE PROBLEM

A large array of factors associated with diabetes-related foot complications and amputations in the community were identified by stakeholders. Further examination of the relationships between these factors and potential mechanisms by which they may be connected to foot health outcomes can be useful in guiding strategic planning of new models of foot care.

The discussion that follows will first explore how the problem of foot complications and amputations is positioned in the context of the health system. The relationships between contributing factors at multiple levels and within the health system will be assessed. In-depth examination of the lack of provision of basic foot care reveals multilevel pathways linking foot health with policy, funding and jurisdictional barriers. Mapping of foot care systems reveals key gaps and potential points of intervention. Finally, the position of the most important stakeholders, people with foot complications and amputations, will be examined in terms of individual responsibility, place and agency.

5.1A MULTILEVEL FACTOR RELATIONSHIPS: THE PROVISION OF BASIC FOOT CARE

The lack of provision of basic foot care in the community was identified by stakeholders as one of the most significant factors associated with foot complications.

Participants reported that few physicians and nurses provided regular foot exams or early foot care to patients with diabetes. Few diabetes patients with foot complications could access basic foot care or appropriate footwear. Hence, primary foot care in the community was inconsistent with diabetes practice standards. Foot examination is considered an integral component of diabetes management in order to decrease risk of foot ulcers and amputation. Foot exams should be performed annually in all adults with diabetes and more frequently in individuals at high risk according to Canadian clinical practice guidelines (Meltzer et al., 1998). In high risk patients, early pathology including callus, nail and skin conditions should be treated regularly (Apelqvist et al., 2000). Footwear can serve as either a protective factor or as a precipitating factor in the development of foot ulcers. Proper footwear is especially crucial in the neuropathic foot to offload abnormal pressures. Inappropriate footwear can contribute to ulceration due to poor fit or accommodation (Uccioli, 2006).

Further exploration of the issue of foot care practice revealed multiple underlying structural level factors. Foot care practice was linked distally to three broad determinants: (1) funding structure, (2) jurisdictional divisions, and (3) policy. Relationships between these variables are complex and nonlinear. Potential pathways linking these determinants with foot care are outlined in Figure 5. In the top pathway, the direct impact of funding arrangements on service delivery and practice is outlined. Foot care was not funded as a distinct program in the community. In addition, foot care services provided to the community were based only on estimated costs and did not meet the actual demand for foot care. Funding for foot care mainly covered the services of a part-time nurse and a diabetes worker. Contract funding of foot care nurse services was negotiated as a tender bid process.

One impact of this funding arrangement on the health system was that there was no central administration of foot care. At the individual level, the lack of a clear mandate for foot care relegated foot exams as well as basic skin and nail care to a lesser priority status. In addition, as a result of inadequate funding levels, the unmet demand for foot care was partly absorbed by providers from other community programs. As foot care was not mandated within these programs, providers had to resort to providing foot care in a discreet manner. Minimal collaboration between providers from different programs and competing work demands resulted in limited and fragmented delivery of foot care.

The second broad determinant that had an impact on provision of foot care was the involvement of different jurisdictions and different funding structures in health care delivery. Physicians practicing in the community are funded by the province. Nurses are employed either by FNIHB under contractual arrangements or by the community within transferred health programs. The impact of multiple administrative structures on the local health care system is limited exchange of information between providers. Providers reported to separate health authorities and were not all equally accountable to the community health administration. Few were evaluated by the community. The impact on providers' practice was that nurses and physicians were able to define their own foot care practice, and were not obliged to follow practice guidelines or practice within the mandate of the health centre.

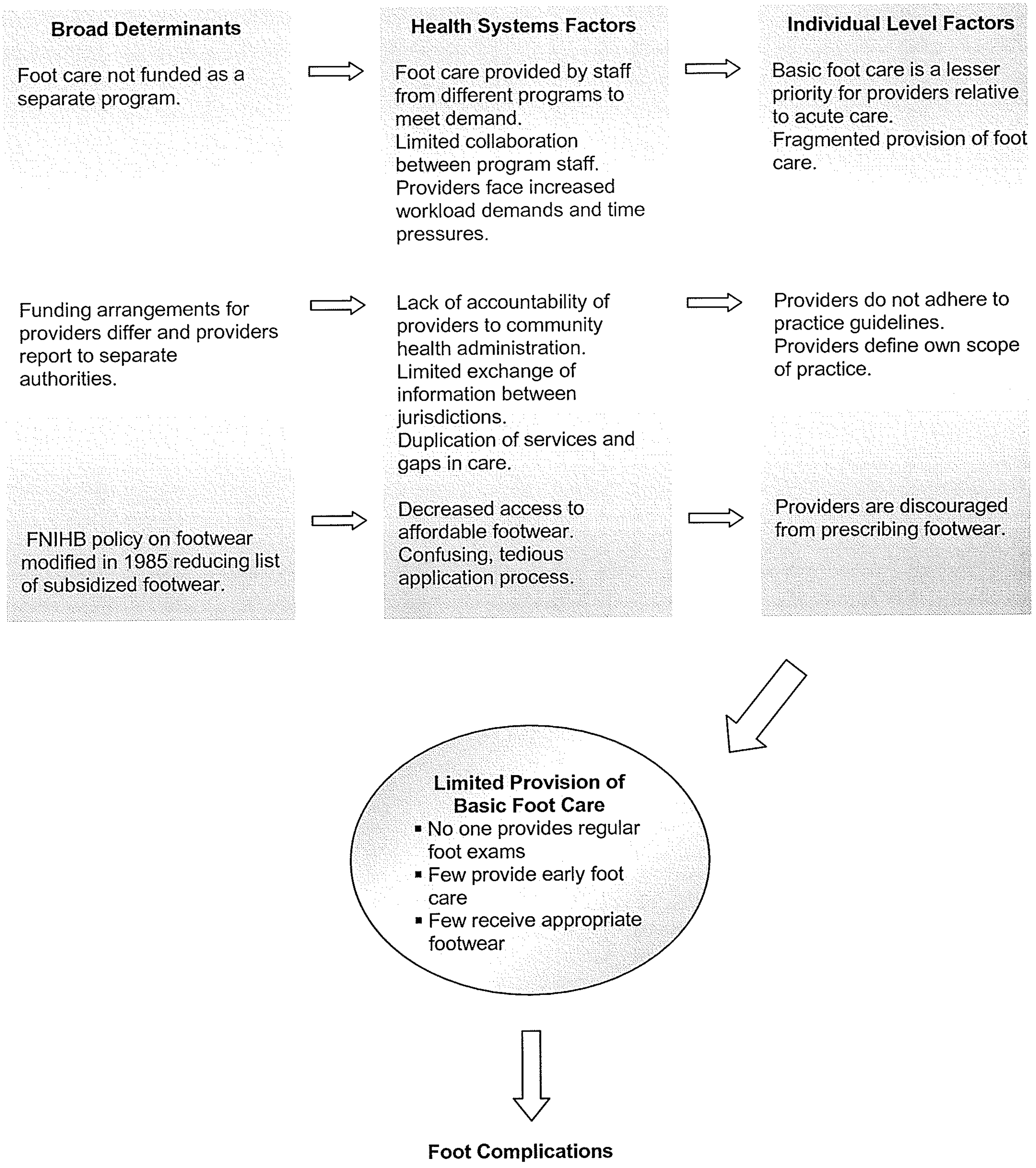


Figure 5
Examining Foot Exams: Factors underlying the lack of provision of basic foot care.

Another broad factor that affected foot care services in the community was the modification of FNIHB's footwear policy in 1985. The impact of the policy changes at the health system level included restricted access to shoes and a tedious application process which discouraged physicians in the community from prescribing footwear when indicated. As a result of restrictions on subsidized footwear, few diabetes patients with foot pathology could afford appropriate footwear. In some cases, patients were able to access orthotics but did not have proper shoes to put them in.

Footwear and foot care are thus tied to funding, policy and organizational systems beyond the actions of individual providers and patients. These systems influence each other but remain disconnected in fundamental ways. For example, policy makers are disconnected from the lives of people and not cognizant of the actual conditions of living in the community. Hence health policies had limited impact on the health and well being of the people. In addition, health funding is not responsive to the needs of the community. In many cases, funding level estimates were insufficient to meet program operation costs. Community health administrators had little control over the allocation of funds leaving little flexibility in delivering effective programs. Finally, providers tended to work in isolation from one another and from the health administration resulting in duplication and gaps in care.

The multilevel pathways underlying the provision of basic foot care underscore the complexity of factors contributing to poor foot health outcomes in First Nations.

Strategies that address change on multiple levels beyond proximal targets are therefore needed to reform foot care.

5.1B SYSTEMS RELATIONSHIPS

Patterns of Foot Care

Examining the relationships between foot care systems as a whole and how people interact with these systems provides a broader understanding of where gaps in foot care exist and why they occur. The schematic diagram in Figure 6 serves as a guide for understanding how people in the community move through foot care systems and how these systems relate to one another.

The health care system is represented in blue at the top of Figure 6. The blue boxes at the top of the figure represent the availability of foot care services within the community, private sector and hospital system. Community services include: diabetes screening, basic foot care services provided by physicians and nurses, diabetes education services such as workshops and counseling sessions, and acute care. Private foot care services consist of podiatry services which include foot exams, foot care and footwear assessments, as well as footwear suppliers. Foot services provided in the hospital system include: acute care day and after-hours outpatient clinics, outpatient care by infectious disease and vascular specialist physicians, emergency department services, and inpatient care.

The delivery of foot care is represented by blue arrows (pointing downward). The size of the blue boxes and arrows reflects the amount of care available and the amount of care delivered respectively. Foot care services were available and accessible to residents in varying degrees. Preventive health services in the community mainly consisted of patient education. Regular screening of diabetes and diabetes complications was not available. Basic foot care services were provided on a limited and selective basis in the community. Foot care and footwear services available through private and hospital-based podiatry and physiotherapy services were also not easily accessible. Many people in the community with foot complications were unable to afford private foot care services or appropriate footwear. Those eligible for subsidized footwear experienced long waits. Footwear providers in hospital physiotherapy and rehabilitation engineering departments were consulted on a limited basis by primary care providers. Foot care from specialist physicians was available in urban hospitals. However, relatively little specialist foot care was actually provided to residents as few patients were referred by primary care physicians. The inability of patients to access specialist physicians despite availability is indicative of weak links between primary and tertiary care systems. Due to lack of coordination between these systems, primary care providers and specialists tended to manage a similar case mix of patients resulting in overlapping services.

People in the community are represented in red (lower section Figure 6). The activity of people in managing their feet is represented by the red boxes. The red arrows (pointing upward) reflect the demand for care. The size of the red boxes and red arrows reflect time spent on the activity, and the amount of demand respectively. People typically entered the primary foot care system after the onset of foot complications. A large proportion of people with diabetes-related foot problems were treated acutely by primary care physicians and nurses in community health centre and hospital clinics. Long waits at clinics prompted some people to seek treatment for acute foot problems in after-hours

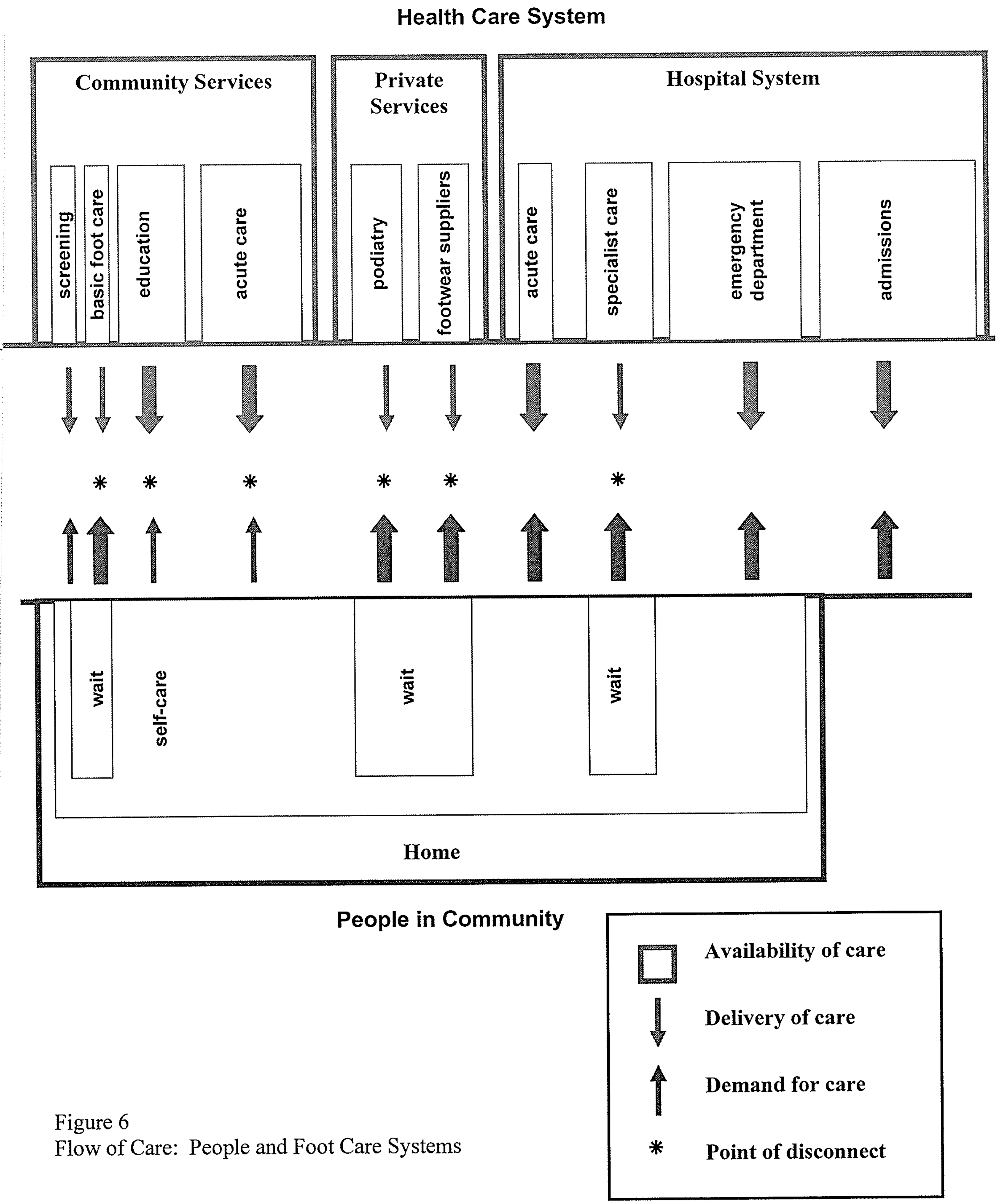


Figure 6
Flow of Care: People and Foot Care Systems

clinics in rural hospitals. People with advanced foot complications were managed independently by primary care physicians. These people routinely entered the hospital system via emergency departments or admission by primary care physicians.

Points of disconnect or incongruence (marked by asterisks in Figure 6) between demand for care and delivery of services (where arrows do not match in size) mark key gaps in care where obvious wait periods occur. Gaps in foot care were most conspicuous upstream as evidenced by waits for basic foot care, footwear and specialist care. While an important indicator of gaps in care, wait times for foot care were neither a complete measure of the need for foot care nor the adequacy of foot care in the community. People with foot problems who were not in contact with the health system could not be tracked and essentially were "waiting outside the system" for care. With few systems in place in the community for diagnosis of diabetes or early detection of foot problems, the system was not able to accurately capture the true burden of disease. Consequently, waits for early diabetes care and early treatment of foot problems were underestimates or were hidden.

The flow of care schematic diagram in Figure 6 serves as a tool for assessing the performance of foot care systems using measures of availability of care, accessibility of services, and use of health services. The limited availability of basic foot care resources in this community greatly disadvantaged the whole system in the management of foot complications. Few people could access early treatment of foot problems. Access to tertiary care such as footwear and specialist care was restricted through funding policies and through the gatekeeper role of physicians. Lack of coordination between systems further impeded access. Consequently, few people received primary foot care within the community health system. The dynamics of the flow of foot care reveal that the availability, access and coordination of care are integral measures of the performance of foot health systems.

Foot Care Systems Dynamics

The diabetes systems dynamic model (Jones et al., 2006) serves as a practical framework for understanding the progression of foot complications in the case of the community. In this model, diabetes progression is conceptualized as a dynamic process that is moderated in varying degrees by preventive care systems. In keeping with the concept of movement through stages of disease, the flow of people in the community through foot care systems reveals key interconnections – most notably the impact of upstream preventive care on downstream management of foot complications. Deficiencies in the primary care system had ripple effects throughout the health care system. Limited early detection initiatives greatly undermined the efficacy of downstream diabetes management efforts. Without formal screening initiatives and routine foot examination, the actual burden of foot complications in the community remained unclear. The problem of foot complications was therefore easily underestimated and not fully captured within the health system. In addition, due to limited availability and accessibility of early care, primary foot care efforts did little to check the onset and progression of foot complications.

A systems view of foot care in the community reveals fundamental imbalances in the delivery of care. The primary care system could engage and accommodate few people upstream. People entered the system late at which point interventions had a lesser impact on disease progression. Consequently, the majority of foot care appeared to take place in the hospital system or in the homes of individuals. Increased focus on the downstream management of advanced foot complications placed high demands on the hospital system. Thus, individuals incurred much of the responsibility of early foot care and ultimately much of the costs of delayed care.

The Evans and Stoddardt model of health (1994) explains some of the limitations of the health care system in responding to health outcomes, and sheds some light on the disconnection between delivery of services and demand for care. The authors propose that the need for care is essentially defined by the health system. The decision as to who needs care is based not only on the health of people, but also on the capacity of the health care system to accommodate this need. Access to care is carefully controlled and adjusted by the health care system according to the availability of resources and the mandate of financial systems.

In accordance with the Evans and Stoddardt critical perspective of health care, the need for foot care in the community was addressed by the health system only where it could most feasibly be accommodated – upstream in the health promotion forum and downstream in the hospital system. The provision of basic foot care is reflective of the priorities of the health system. Access to basic foot care was selectively controlled by diabetes providers independently of foot health status. Access to foot exams was adjusted to compensate for the competing demands of acute health problems. Patients with chronic disease were directed further downstream for care. Footwear policy was regulated to offset increasing health care costs. Delays and waits for foot care, reflecting unmet demand, occurred at many points in the system. This demand was only partially captured in wait lists that few providers acknowledged or attended to. Few diabetes providers in the community were aware of the actual prevalence of foot complications in the community. Resistance to formal screening initiatives in the community reflected the reluctance of health administrators to increase access to diabetes care and to test the capacity of the system to meet actual demand. Consequently, foot care systems remained fundamentally disconnected from foot health.

The health system faces continual tensions between the increasing need for care and increasingly restrained resources. In the allocation of scarce resources, economic tradeoffs occur such that different policies benefit individuals differently (Evans & Stoddardt, 1994). As a result of the increased focus of preventive care on education in the community, fewer resources were directed toward the secondary prevention of foot complications. Hence, the prioritization of primary care prevention over secondary prevention initiatives privileged the interests of those might become ill over those who are ill.

5.2 SITUATING THE INDIVIDUAL

5.2A THE PREVENTION DISCONNECT AND THE SHIFTING BURDEN

We move to examine the place of people with foot complications within the health care system in an effort to reorient planning strategies toward the health and wellbeing of individuals – the end goal of systems change. An exploration of primary prevention strategies sheds light on the priorities of the system and reveals interesting implications for individual responsibility.

A high proportion of resources for diabetes care was directed toward the education of residents on diabetes and diabetes management. Most providers valued diabetes education as an important part of their practice. In some cases, diabetes education dominated the practice of foot care providers and took precedence over the treatment of foot problems. Despite the considerable attention directed to education, uptake of education initiatives appeared to be low. Few residents participated in community education programs. Providers questioned the knowledge base of patients. Many participants questioned the effectiveness of diabetes education initiatives in the community.

The lesser status of foot care relative to education in the primary care system is reflective of the system's priorities. The health administration had embraced the shift from treatment to health promotion, as did much of the public health profession in the 1980s (Doucette, 1989), but held a limited definition of prevention. Administrators did not recognize screening and early detection of foot problems as a significant aspect of the health centre's mandate for prevention. Providers questioned the value of regular foot assessments. Many believed that it was "too late" for individuals who had already developed foot complications. Consequently, few options were available within the health system for the many individuals with existing foot complications and for those who had not yet been diagnosed. Thus, in a health system which prioritized primary prevention over secondary and tertiary diabetes prevention strategies, individuals with diabetes-related foot complications and amputations occupied a lesser place.

The focus of health education in the community rested mainly on lifestyle and behaviour change. The system privileges the proactive individual who looks after her/himself. The individual is regarded as both helpless and autonomous in the health system sending contradictory messages to residents as to how to participate in care. The message of taking care of oneself appears to have been so successful that even patients with major illness were reluctant to see a physician. The message, however, is incomplete as it disregards the structural/environmental conditions which impact lifestyle and choice.

The biomedical paradigm locates responsibility for illness in the individual often placing blame on the ill. The individual who is ill is held responsible for having taken health risks and for making unhealthy choices (Donahue & McGuire, 1995). The notion of health as a personal responsibility suggests that health status is under the control of individuals. Feeding into the stigma surrounding the disease, individuals with diabetes are held responsible for developing complications.

The prioritization of diabetes education in a community with finite resources has important implications on how responsibility for the management of foot problems is shared. By shifting the responsibility of foot care onto the individual, the system is able to reduce demand and conserve limited resources that are largely controlled by the state. Health education in the community may be viewed as "a means of directing individuals to take responsibility for their own health status, and in doing so, reducing the financial burden on health care services (Lupton, 1995)." Modification of the federal footwear policy successfully quelled the increasing demand for shoes and escalating costs by reducing access. The system is therefore able to influence perceptions of responsibility for health without providing the structural supports to satisfy health needs (Donahue et al., 1995). Ultimately, people with foot complications and amputation are left to shoulder the burden of illness alone.

5.2B AMPUTATION AND THE LOSS OF PLACE

For people with diabetes foot complications, physical loss sustained at an advanced stage of disease was compounded by the loss of place within an overburdened health system and an economically deprived community. In this context, diabetes-related foot complications appeared to hold fleeting importance. Foot complications occurring at an early stage were not acted upon by health care providers struggling to cope with other complications of diabetes and with infectious diseases. For many residents, early foot problems were overshadowed by more pressing concerns of inadequate food and shelter. Advanced foot lesions tested the tenacity of a self-sufficient community and the capacity of a fragile health system. Diabetes providers in the community were ill equipped to fully master the art of a treating a foot ulcer. Community residents lacked the most basic of resources including healthy food and supportive footwear, as well as sufficient support to adequately manage foot lesions at home. Under these conditions, seemingly benign foot problems exacted a high cost.

For people living in these conditions, amputation was a transformative experience. People with foot complications and amputation were especially vulnerable to structural barriers in the community. After amputation, people in the community became easily displaced and increasingly disconnected from the health system. At advanced stages of disease, amputation offered a quick and humane solution to the problem of managing foot complications, and a way of moving people out of the costly hospital system. After amputation, people appeared to place fewer demands on the health system. In fact, many people had difficulty connecting with the health system. Many had lost the ability to walk comfortably. They could not easily access care because the local transportation system was not wheelchair accessible. They did not feel connected to diabetes programs that privileged primary prevention of disease. Others could no longer continue their life work. In a community with scarce resources, employment and recreational opportunities were virtually non-existent for this group. Consequently, people with amputation became disengaged from both the health care system and the social environment. These individuals became increasingly less visible in the community, experiencing a profound loss of place.

It is in the loss of place and loss of "substantive freedoms" sustained by people living with foot complications and amputations that the real magnitude of this disease may be measured.

> The success of a society is to be evaluated, in this view, primarily by the substantive freedoms that the members of that society enjoy. . . . Having greater freedom to do the things one has reason to value is (1) significant in itself for the person's overall freedom, and (2) important in fostering the person's opportunity to have valuable outcomes. Both are relevant to the evaluation of freedom of the members of the society and thus crucial to the assessment of the society's development (Sen, 1999).

Thus, individuals are robbed of exercising their capabilities, and both the community and society are deprived of the unique contributions of these individuals.

CHAPTER SIX

CONCLUSION

6.1 MAJOR THEMES

This thesis has examined the problem of diabetes-related foot complications and amputation in one First Nation community, and the function of the health system in the management of this problem in order to identify structural factors associated with poor foot health outcomes. The evidence gathered confirms the magnitude of type 2 diabetes in the community to be considerable, measured not only by the prevalence of complications but also by the impact of the disease on the health system, the community as a whole and its people. We found a health system functioning in a state of crisis, a community devastated by the loss of generations of family members, and individuals living with foot ulcers and amputation very much alone in managing their health.

A complex array of factors contributing to the problem of diabetes-related foot complications and amputations in the community were identified at the individual level, at the health systems level, and at the broad determinant level. Individual level factors were intertwined with factors in the health care environment. Health systems and individual level factors were ultimately embedded in the broader social, economic and political environment.

Two major themes unify the experiences of nurses, physicians, administrators and people working and living with foot complications in the community.

1. The theme of disconnection:

Disconnection was present between systems, between people in the community, and between people and the health system as a whole. Mapping the flow of foot care through community, hospital and private health systems revealed several points of disconnect. Health providers in the community generally worked independently of each other. Physicians and nurses funded on a contract basis were largely unaccountable to the health administration. Primary and tertiary foot care systems were poorly linked as a result of limited collaboration and communication between providers, lack of consensus on wound care and the lack of clear referral paths. Lack of coordination of foot care between systems resulted in duplication, gaps and delays in care. In addition, without a formal surveillance program in place the system was fundamentally disconnected from foot health outcomes. Registries and wait lists did not fully capture the actual burden of diabetes foot complications in the community. Consequently, the health system regulated foot care delivery according to the resources available and the use of services. The system thus remained unaccountable to the problem of foot complications and amputations.

The health system and the people in the community were disconnected in several ways. People did not connect early or regularly with the primary care system in the community. Low participation patterns were a reflection not only of individual knowledge, beliefs and values but also of issues of access to care. The system was not connecting with people in fundamental ways. Basic primary foot care, advanced foot care from specialist physicians, and footwear were not accessible to people in a timely manner. Health education messages promoting healthy lifestyles were not congruent with the economic reality of people's lives in the community and did not take into account the structural barriers that limited healthy choices.

People in the community were disconnected from each other in fundamental ways. In addition to experiencing racism and negative stereotyping outside the community, as well as the stigma of diabetes inside the community, people with foot complications and amputations were further marginalized by a health system that excluded them as a lesser priority. With limited access to transportation, few social supports and recreational opportunities in the community, many people were extremely isolated. Elderly people living alone and on social assistance were particularly vulnerable to isolation and neglect.

2. The theme of inequity:

As we move beyond the level of the individual to the realm of health systems, and economic and political environments, the collective responsibility of governments and greater society for protecting the diabetic foot becomes apparent. In the health system, the distribution of health services privileged primary prevention and acute care thereby excluding individuals with chronic foot complications and amputations.

Funding systems did not adequately support chronic disease management in the community despite the fact that diabetes and its complications dominated the practice of physicians and nurses. Funding levels for diabetes care were based on estimates not actual health outcomes in the community and were therefore insufficient for the delivery of adequate primary foot care. Contribution funding arrangements for health programs did not support flexibility in allocation of dollars to areas of greatest need. Decisions on allocation of funding for health programs were not a shared process and often excluded program managers and providers who were responsible for delivering the programs.

Consequently, it is the people with foot complications and amputations, one of the most vulnerable groups in the community, who must bear full responsibility for managing their feet without supports, without a voice or place in the health system. In the predicament of these individuals, there is both inequity and injustice.

6.2 RECOMMENDATIONS

The themes of disconnection and inequity provide a strong framework for the development of a foot care strategy in the community. Based on the evidence gathered in this study, I put forward following recommendations to support optimal foot care delivery: (1) Integration of foot care systems, (2) balance in the delivery of foot care, and (3) equitable policy. The first two recommendations target systems change. The final recommendation addresses the challenging yet powerful policy environment.

1. Integration of foot care systems and people:

Connections between people and systems may be strengthened in several ways. People in the community must be engaged more meaningfully in the care process. People who have experienced foot complications and amputation can serve as a powerful resource and may be included in diabetes care in peer advocacy and health planning roles. Holistic health promotion and health education policy is needed that recognizes the structural barriers that people face in managing their health. In order to be respectful of the position of the individual, health promotion messages must reflect the shared responsibility of providers and policymakers in diabetes management.

Information systems and people need to be linked in practical ways. This can be partly achieved by centralizing health records. A system of monitoring health service use and delivery provides a tool for measuring standards of care. This creates transparency within the health system and possibly an incentive for changing provider practice. Tracking health status and wellbeing allows health outcomes to be used as a measure of the performance of health systems.

Stronger health networks between foot care systems can be established by expanding partnerships between providers. This would enable clear, direct referral paths between primary and tertiary care systems. Increased provider education and training initiatives across disciplines and jurisdictions are also needed. This would facilitate consensus building between providers on such issues as referral criteria and wound care.

2. Balance and continuity in delivery of foot care:

Foot care needs to be delivered in a balanced manner to support patients, not only at early and ends stages of foot disease, but throughout the course of foot problems they may experience. Adequate foot care must therefore be available and accessible in the primary care system.

In addition, balance in the workload of physicians and nurses is needed so that providers are not continually overburdened. A centralized triaging system is one option for re-directing care. Streamlined referral paths can prevent duplication of services between disciplines. Building capacity of lay providers in early foot care through continuing education and increased mentorship can also help redistribute provider workloads.

3. Equitable foot care policy:

Foot care funding arrangements need to be reviewed so that health funding for diabetes in the community more accurately reflects the needs of patients and the community. Funding formulas must be accountable to foot health outcomes in order to be equitable. At the very least, funding levels for foot care in a community with more than 3000 people need to be consistent with other populations in Canada of comparable size and health status.

Finally more strategic allocation of existing health funding is needed. Greater investment in upstream initiatives such as footwear for all people with diabetes is cost effective. Greater flexibility in funding arrangements is needed also to allow front line providers some autonomy in delivering care where it is most needed. Cost sharing between governments in such initiatives is needed to break down jurisdictional barriers and disincentives.

6.3 DISSEMINATION OF RESULTS

The results and recommendations of this study were presented to the community Diabetes Working Group in July, 2007. The presentation stimulated further discussion on current issues surrounding foot care that stakeholders continued to wrestle with. Situated front line to these issues, members of the Working Group each faced unique challenges in delivering health care in the community and were each absorbed with different components of foot health systems. Health providers expressed frustration with wait lists for foot care and the inability to deliver sufficient care with limited human resources. Program managers expressed uncertainty as to how to redistribute workloads among providers burdened with multiple responsibilities. Program administrators struggled with how to continue to operate thinly stretched health programs while facing further cuts in health spending by the federal government.

The shifting policy environment presented one of the biggest challenges to delivery of adequate diabetes care in the community for health administrators. Administrators reported that FNIHB was planning to discontinue foot care nursing services to First Nations people living off reserve. The community was also facing serious cuts to the medical transportation services budget, according to health administrators. In recent discussions with the community, FNIHB had announced that funding for transportation for dialysis treatment would only be provided for a period of four months. After this time, transportation services would be discontinued and community residents requiring dialysis would be expected to relocate to a centre that provided such care. Deeply concerned that the change in transportation policy would impact a large proportion of community residents, health administrators were meeting with local and national political First Nation organizations in order to respond to the policy change.

The meeting with the Working Group provided verification of study findings as relevant within the challenging policy and health care environment facing the community. Members of the Working Group were receptive to the findings of this study and remained committed to addressing the problem of foot complications and amputations as a priority. On the request of the community health administration, I prepared a brief report of the thesis and submitted it to the administration in November, 2007. Administrators indicated that information from this study would be used to inform future community health planning efforts.

6.4 RELEVANCE OF STUDY

This research has identified some of the major proximal and distal structural barriers associated with diabetes-related foot complications and amputation in one First Nation community in southern Manitoba. The information gathered serves as a tool for the community for further strategic health planning and policy development toward an optimal model of foot care delivery. The structural factors contributing to foot complications are not directly generalizable to other populations. However, these factors can serve as an evidence-based framework of measures of foot care system performance, and provide a template of general principles for a foot care model that may be tested in other First Nation communities in Manitoba and Canada.

This in-depth exploration of diabetes foot complications and foot care systems in a First Nation community in southern Manitoba with one of the highest rates of diabetes and diabetes-related amputation in the province, may contribute to an understanding of the variation in diabetes and amputation rates among First Nations in Manitoba. This work is based on the perspective of multiple stakeholders of diabetes, and is one of few studies of First Nation health services in the literature that is grounded in the voices of First Nation people.

The structural barriers identified in this thesis are a clear indication that the discourse of diabetes complications in First Nations needs to be expanded beyond the individual level to recognize the role of systems, and economic and political determinants of health. As the health priorities of governments continue to be tested in the current climate of fiscal restraint, the evidence gathered in this study serves as a reminder that health policy should be essentially connected to the health and wellbeing of people, and that health systems are not an end but a means to this goal. Finally, the study upholds the premise that the more vulnerable members of a community – individuals living in poverty and individuals living with amputation – ought not to bear the greatest cost of unequal distribution of finite health resources.

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APPENDIX A: INTERVIEW GUIDES

INTERVIEW GUIDE – NURSE & ALLIED DIABETES PROVIDERS

- How long have you been working in this community?
- Can you describe your role as a health care provider in this community?
- What are your thoughts about diabetes foot complications in this community? About amputations?
- Can you describe your experience working with people with diabetes in the community?
- What services, programs or resources are available for people with diabetes in the community?
    - What services are most heavily used?
    - What services are least used? Why?
- Can you describe the role you have in foot care?
- Who else provides foot care in the community?
- Can you describe the referral process of patients with foot complications?
- What appears to be working well in the management of diabetes complications?
- What is not working well?
- What challenges have you faced in managing diabetes foot complications in this community?
    - Can you give an example?
- What do you think are the major challenges that patients with diabetes face?
- Some communities seem to fare better than others in managing diabetes and complications? Why do you think this is?
- What suggestions do you have to change diabetes care/diabetes foot care in the community?
- Is there anything else you'd like to talk about?

INTERVIEW GUIDE – GENERAL PHYSICIANS

- How long have you been practicing in this community?

- What are your thoughts about diabetes foot complications in this community? About amputations?

- Can you describe your experience working with people with diabetes in the community?
  - What kinds of cases do you typically see?

- Can you describe your approach for treating the typical patient with foot complications?

- How do you approach treating patients with advanced foot complications?
  - Can you explain the decision-making process?

- Can you describe the referral process of patients with foot complications?

- What services, programs or resources are available for people with diabetes in the community?

- What challenges have you faced in managing diabetes foot complications in this community?
  - Can you give an example?

- What are the major challenges that patients with diabetes face?

- What appears to be working well in the management of diabetes complications?

- What is not working well?

- Some communities seem to fare better than others in managing diabetes and complications? Why do you think this is?

- What suggestions do you have to change diabetes care/diabetes foot care in the community?

- Is there anything else you'd like to talk about?

INTERVIEW GUIDE – SPECIALIST PHYSICIANS

- What are your thoughts about diabetes foot complications in First Nation communities in Manitoba?
- Do you see many patients from [this community]? From other First Nation communities?
- Can you describe your experience working with people with diabetes in the community?
    - What kinds of cases do you typically see?
- Can you describe your approach for treating the typical patient with foot complications?
    - Are the indications for treatment fairly straight forward?
- How do you approach treating patients with advanced foot complications?
    - Can you explain the decision-making process?
    - What cases do you consider to be priority or urgent?
- What are your thoughts about amputations in the community?
- Do you believe non-traumatic amputations are preventable?
- Can you describe the referral process for patients with foot complications?
- The rate of specialist consults is much lower in some First Nation communities than others despite high prevalence of diabetes according to recent research. Why do you think this is?
    - Do pts show up for their appointments with you?
- What challenges have you faced in managing diabetes foot complications in this community? In other First Nation communities?
- What appears to be working well in the management of diabetes complications in First Nation communities? What is not working well?
- Some communities seem to fare better than others in managing diabetes and complications? Why do you think this is?
- What suggestions do you have to change diabetes care/diabetes foot care in the community?
- Is there anything else you'd like to talk about?

INTERVIEW GUIDE - ADMINISTRATOR

- Can you describe your role as a health administrator in this community?
- What are your thoughts about diabetes foot complications in this community? About amputations?
    - What trends have you observed?
- Can you describe your experience working with people with diabetes in the community?
- What types of services, programs, and resources are available for people with diabetes in the community? For people with foot problems?
    - Which services are most heavily used? Underused? Why?
- How are these services funded?
- Are these services monitored or evaluated in any way?
- How is diabetes care coordinated or organized in the community?
- Who provides foot care in the community?
- What happens to patients requiring specialized foot care?
- How well are current diabetes programs/services meeting the needs/priorities of this community?
    - What appears to be working well in the management of diabetes?
    - What is not working well?
    - What challenges is the health care system experiencing?
    - Do you have any other concerns?
- What are the major challenges that patients with diabetes face?
- What suggestions do you have to change diabetes care/diabetes foot care in the community?
- Do you know of any relevant documents in the community related to diabetes?
- Is there anything else you'd like to talk about?

INTERVIEW GUIDE – COMMUNITY RESIDENTS

- What has your experience been like living with diabetes in the community?
    - What has it been like taking care of your health?
    - What has helped you better manage your diabetes?
    - What things have made it difficult for you to manage your diabetes?

- Can you describe the care you have received for diabetes?
    - Have you seen a health care professional regularly for your diabetes? What was that like?
    - Have you visited any specialists for your diabetes? What was that like?
    - What services, resources or programs did you find most helpful?

- Can you describe the problems you have had with your feet?
    - What was this like?

- What has it been like for you taking care of your feet?
    - What things were helpful in taking care of your feet?
    - What things made it difficult for you to take care of your feet?

- Can you describe the care you have received for your feet?
    - Have you ever had your feet checked?

- Can you tell me about the amputation(s) you have experienced?
    - What was this like for you?

- What kind of care are you receiving now for your diabetes?
    - How do you feel about this?

- What do you think about the diabetes programs and services in the community?

- What things would you like to change to help people with diabetes in the community?
    - What things would have been helpful for you in managing your diabetes?

- Is there anything more you'd like to talk about?