Development of diabetes prevention interventions with First Nations communities

MHS Essay

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ABSTRACT

Type II diabetes mellitus is a major cause of morbidity and mortality among North American Natives. This study examines the prevalence of known risk factors for and concepts of diabetes in three Northwest Ontario First Nation communities and the potential for adaptation of community-based prevention interventions developed in the Sandy Lake First Nation. A combination of participatory and traditional ethnographic approaches was used to generate knowledge and pilot interventions. Communities were eager to address the increasing epidemic of diabetes, but often had limited knowledge about methods for prevention. Other barriers included limited access to healthy foods and preventive health services. The most popular proposed intervention was a school-based prevention program. There is great need and potential for community-based diabetes prevention among Native communities in this region.

KEY WORDS

Native American, type 2 diabetes mellitus, participatory research, Ontario, Sandy Lake, First Nations, aboriginal health, diet, obesity

INTRODUCTION

Type II diabetes mellitus is a serious health problem in Native North American populations (Young *et al.* 2000). In Canada, several studies have documented rates of diabetes 3 to 5 times higher than the prevalence in the general Canadian population (Young *et al.* 2000;Brassard *et al.* 1993;Delisle and Ekoe 1993;Harris *et al.* 1997). Studies of North American Natives with diabetes have shown high rates of cardiovascular disease (Howard *et*

al. 1995;National Steering Committee for the First Nations and Inuit Regional Health Survey 1999), renal failure (Narva 2002;Dyck and Tan 1994), and retinopathy (Ross and Fick 1991). Rates of end-stage renal disease (ESRD) in some Native populations have also been documented to be higher than that in non-Natives (Dyck and Tan 1994), much of which is attributable to diabetes. The remote location of some aboriginal populations makes following recommended diabetes management guidelines more difficult, and exacerbates the impact of some complications. For instance, patients with ESRD from remote reserves must leave their communities permanently if they go on hemodialysis. While improved techniques for management of diabetes in aboriginal people are important, even more essential is the implementation and evaluation of appropriate community-based strategies to prevent diabetes in the first place. This is evidenced by the choice of diabetes prevention as one of the first initiatives targeted by the Canadian Institute for Health Research's newly formed Institute of Aboriginal People's Health. An important part of planning such interventions is the participation of Native communities in the development process. This paper describes the process of working with three Northwest Ontario First Nations to explore concepts of diabetes and plan for a future trial of a community-based prevention intervention.

Participatory Research

In their review of participatory research in health promotion in Canada, Green, et al. define participatory research as "systematic inquiry, with the collaboration of those affected by the issue being studied, for purposes of education and taking action or effecting social change"(Green 1995). Participatory research in Native Canadian populations has been common in urban groups and in the fields of education and communication (Castellano

1993;Jackson 1993). More recently, participatory methods have been used in addition to traditional qualitative methods to understand concepts of Native health such as diabetes (Boston *et al.* 1997;Dickson and Green 2001;Davis and Reid 1999;Potvin *et al.* 2003). The few existing diabetes prevention studies in Canada (Kahnawake, Okanagan, and Sandy Lake) have all used participatory approaches with success (Macaulay *et al.* 1997;Daniel *et al.* 1999;Harris 1998). This kind of collaboration is important because although there have been positive research partnerships, there have also been studies that left Native communities feeling exploited or betrayed (Davis and Reid 1999). Some Natives have perceived that researchers do not appreciate the diversity in Native culture and instead categorize all groups as Indian (Davis and Reid 1999). Even in studies supported by Native communities, members have suggested that increased inclusion of community opinions, and community members in the intervention team might have improved results and benefits of the study (Special Working Group, 2000). It is therefore essential to foster understanding of different aboriginal cultures and include communities in the development of research projects. This study was designed to follow this direction, using a flexible, exploratory approach.

To this end, a blend of participatory and traditional ethnographic methods was used. This provided rich descriptive data on the situation in each community while allowing community members to voice their opinions and direct the progression of activities. Semi-remote communities eligible for participation were invited to an informational meeting and those expressing the most interest were invited to participate in the study. To ensure a diverse sample, a remote community was also invited to participate.

The Sandy Lake Health and Diabetes Project

One of the few prior studies that has partnered with a Native community to develop prevention programs is the Sandy Lake Health and Diabetes Project (SLHDP). Sandy Lake First Nation is a remote northwest Ontario Ojibwa-Cree community with over 2100 band members, about 300 of whom live off reserve. It has year-round fly-in access to its air strip, but only winter road access. There are elementary and high schools, stores, and nursing station on reserve. Residents must fly out to receive hospital care. Written and spoken Oji-Cree is the primary language for the older generation, while English is the primary means of communication for the younger generation. Many younger people speak and understand some Oji-Cree as well.

The SLHDP partnership was conceived in 1991 when the Sandy Lake First Nation sought assistance from researchers in addressing their increasingly visible diabetes epidemic. The investigators and community leaders meet regularly to discuss all aspects of the project, including study protocols, funding, new initiatives, personnel, and publications. All protocols were approved by the Sandy Lake First Nation Band Council and the University of Toronto Ethics Review Committee.

The original goals of the project were to determine the prevalence and risk factors for diabetes in the community, and to develop culturally appropriate strategies for primary and secondary prevention of diabetes and its complications. The SLHDP has done this through a survey of risk factors, screening for diabetes, and a community-based diabetes program. The diabetes program has included a weekly radio show, Home Visit program, the Northern Store's Healthy Food Choice Program, community events, and a School Diabetes Prevention Program that included a health curriculum for 3rd and 4th grade students.

The initial survey and screening helped determine the areas on which to focus prevention activities. Results showed the age-adjusted prevalence of diabetes to be 26.1%. The age-adjusted prevalence of impaired glucose tolerance (IGT) was 13.6% (Harris *et al.* 1997). Risk factors associated with diabetes in Sandy Lake included obesity, high fat and low fibre intake, and genetic factors (Harris *et al.* 1997;Wolever *et al.* 1997;Gittelsohn *et al.* 1998;Hegele *et al.* 1999). In addition, low levels of physical activity were found to be associated with obesity and elevated insulin levels (Hanley *et al.* 2000;Hanley *et al.* 1997). Based on these findings and additional formative research, the community diabetes program was developed. The Sandy Lake School Diabetes Prevention Program demonstrated increases in dietary knowledge, self-efficacy, and intention, and decreases in television watching associated with the program. (Saksvig *et al.* 2002) The local Northern grocery store cooperated in a program to identify and increase sales of foods that were low in sugar, low in fat, and high in fiber using shelf labels. A home visit program brought individualized teaching on nutrition, health, and physical activity to interested families. (Harris, SB, et al. manuscript forthcoming) In addition, the SLHDP broadcast a weekly radio show on topics related to diabetes and participated in promoting community events such as health fairs and construction of walking trails.

Scaling up SLHDP

Although the SLHDP interventions had positive outcomes, they targeted only one remote community. The Kahnawake and Okanagan interventions were also limited to a single community each. Despite increasing efforts to improve management of diabetes, widespread prevention programs are still lacking. (Young *et al.* 2000) Since the SLHDP interventions had proven successful in that setting, the next question became whether they

could be scaled up to other reserves with different characteristics. Although reserves in Northwest Ontario share many similar health issues and cultural characteristics, each is unique. This presents a challenge to implementing a community-based intervention in several reserves. Some reserves have independent Native administered schools on reserve, while other send their children off reserve to public schools in non-Native communities. Primary food sources may be on or off reserve. Even among on reserve stores there are both chain stores such as Northern, and locally owned stores. Health infrastructure varies as well between larger and smaller reserves, remote and semi-remote reserves, and bands that have taken transfer of authority for services from First Nations and Inuit Health and those that still receive provincially administered health services. These variations need to be taken into account when developing an intervention with multiple communities.

In addition, there is a continued need for partnership with communities and understanding of Native concerns. All of the communities were Ojibwa, but as previously noted, varied in many ways. We will explore how the differences and similarities may affect implementation of appropriate diabetes prevention strategies.

METHODS

Setting

All three communities are located in Northwest Ontario. Most of the non-Native communities lie in the southern half of this region, while further north Native communities are the only permanent settlements. There are over 60 First Nations with on reserve populations ranging from 60 to 2000. Often as many as half of registered band members of a particular First Nation may not live on their own reserve, residing instead in towns or

cities or occasionally on other reserves. Most of the reserves in the southern region have road access to nearby non-Native communities, but in the north most reserves are isolated by the vast boreal forest and numerous lakes.

Community A is a semi-remote reserve with fewer than 400 band members, about one-third of whom live off reserve. It has year-round road access, and many residents travel off reserve on a daily basis to work, attend school, go shopping, and access healthcare in nearby towns. Most services are located in a town of about 9,000 predominantly non-native residents. Native students are a minority at their off-reserve schools. Syllabics are not used, and English is the primary language of most residents, although elders and most individuals over 40 still speak and understand some Ojibwa.

Community B is also a semi-remote reserve with fewer than 300 band members, almost half of whom reside off reserve. Residents access services in the same town as Community A and share similar lifestyles. Primary school students attend an off-reserve school where the minority of students are non-Native and the majority of students are from a larger neighboring reserve.

Community C is a remote reserve with approximately 2000 band members, about 800 of whom reside off reserve. It has year round fly-in access to its airstrip, and when weather permits, a winter road is constructed over frozen lakes. There are an education centre (K4 though 10th grade), stores, and nursing station on reserve. Residents must fly out to receive hospital care. Written and spoken Ojibwa are the primary language for the older generation, while English is the primary means of communication for the younger generation. Many younger people speak and understand some Ojibwa as well.

Recruitment

Three communities were invited to participate in the study. Two of the communities came from a group of First Nations that attended presentation about the SLHDP and the possibility of a new diabetes prevention project. This presentation was a result of the local tribal health authority's commitment to increasing diabetes prevention, and a local healthcare provider making the recommendation to contact one of the study's principal investigators. The two communities that had the greatest representation at this presentation and showed the most interest were invited to participate. The third remote community was asked to participate on the recommendation of another healthcare provider contacted by the principal investigator.

Procedure

Participatory research is not bounded by quantitative or qualitative methods, but by the locus of power, who controls the research process.(Cornwall and Jewkes 1995) In our study a variety of qualitative and quantitative methods were used, in both a participatory and traditional ethnographic manner. (Table 1.) This blend provided for efficient in-depth investigation with direction from community members as to what would benefit their community the most. In many cases, community members indicated who should be interviewed or what sort of activities would work. The survey was developed primarily by the researchers with input from a local research assistant who performed most of the surveys. In addition to the survey we conducted semi-structured in-depth interviews, group activities, demonstrations, observations, and follow-up discussions with participants. Selection of methods changed as the project moved forward as we heard from community members and as we discovered which methods worked and which did not. All qualitative and some quantitative data were collected by a public health faculty member and a master's

of health science student/ registered nurse. Local Ojibway-speaking research assistants were trained on-site to carry out the survey and organize activities. The majority of interviews and surveys were conducted in English. A few elders preferred to conduct interviews or surveys in Ojibway, which were translated by a local assistant.

Interviews were open-ended, but based on eight interview guides for elders, community leaders, men, women, diabetics, healthcare providers, store employees, and school staff. Interviews were usually conducted with one participant, but four interviews included two or three respondents. Participants were asked about changes in the community, activities, causes of diabetes, ways to manage diabetes, resources for health care and education, foods, community issues, hopes, and recommendations. In the three communities a total of 81 interviews were conducted. (Table 1.) The interviews were tape recorded and later transcribed, unless the participant preferred not to be recorded.

The researchers and local assistants planned and facilitated community meetings to provide a forum for community members to discuss their community and its health concerns and resources. These were promoted with notices, radio/TV announcements, and by word of mouth. We found that meetings targeted at particular groups, such as women, men, or parents, were more successful. We also visited existing activities such as an elders exercise class and elders luncheon to work with certain interest groups. These were sessions organized by local staff where we were allowed a brief session to talk with the attendees. Activities at group sessions encouraged participation in knowledge generation about the community. These included discussing questions about diabetes, making seasonal calendars depicting levels of activity throughout the year, voting on proposed interventions, diagramming health resources and problem solving. Each of the activities was used as a

discussion point to further explore issues and understanding about health and diabetes. On average five to seven people participated. Women attended more frequently than men.

The researchers also conducted informal direct observations at stores and of students at schools to note eating, purchasing, and activity patterns as well as available food selection. Observations at the school were of snack time, lunchtime, classes (including physical education) and recess.

A sample of band members over 18 and living on reserve were randomly selected to participate in a survey (n=72). The survey was a modified form of the original risk factor survey conducted in Sandy Lake, and assessed diabetes history, risk factors for diabetes, activity, food intake, sociodemographic variables, thoughts about diabetes, and preferences for intervention methods.

Piloting of potential intervention strategies included demonstration of SLHDP interventions and other potential intervention strategies. Researchers tested lessons from the SLHDP School Diabetes Prevention Program Curriculum with 3rd and 4th grade students at the elementary school serving each of the three communities. Health workers and diabetics were invited to be guests on a live television call-in show about living with diabetes. An audio drama on kidney failure was played for small groups and broadcast on air with a call-in session. A store on the remote reserve was asked to stock 1% milk to test labeling and promotion of a healthier product. Demonstrations and slide shows of healthier cooking and eating were done at a supermarket serving the semi-remote reserves and a flea market on the remote reserve. A group presentation of a home visit lesson was conducted.

Written consent was obtained for all respondents participating in in-depth interviews, surveys, or discussion groups. All research was approved by the Ethic Review Board of the

University of Western Ontario and the Committee on Human Research of the Johns Hopkins Bloomberg School of Public Health.

Data Management and Analysis

In-depth interviews, group activities, and observations, and discussions were taped or recorded in notebooks. The tapes and notes were transcribed into Microsoft Word and coded for different topics using N5 (QSR International, 2000) software. Discussions with key informants and local research assistants helped to direct further activities and confirm or refine ongoing content analysis. Additional qualitative analysis was done with N5. Survey data were recorded on forms by the researchers or local research assistants. Results were entered in Microsoft Access. Quantitative analysis was done by the research coordinator at University of Western Ontario using the Statistical Package for Social Sciences (SPSSPC, 1995.).

RESULTS

Unless otherwise indicated, results are generalized for all three communities. As noted earlier, these communities have many similar health issues, but vary in resources, and therefore needs. In addition, different interest groups within each community sometimes voiced different concerns, and these are also described.

Community health needs and concerns

While each community emphasized different health concerns, all commented on the increase in illnesses:

> During the time that I remember, my childhood, there was very little, almost no sickness…I think that [youth and children] are probably going to experience much more of these problems, an increase in illness or disease that develop from our adopting a different diet.

Diabetes was noted to be affecting more and more Native people at a younger age. In the

words of one CHR, "…I've noticed when I first started off [over 20 years ago] we didn't have very many diabetics. It was mainly our elders that were that…had this diabetes. But now, like just recently, it's getting younger and younger." At least one diabetic in each community had suffered from renal failure, and eventually lost their life to it. Other illnesses such as cancer, heart disease, asthma, and arthritis were also mentioned as being on the increase. In Sandy Lake diabetes, cancer, heart disease, and asthma were also commonly mentioned and ranked among the most severe diseases (Gittelsohn *et al.* 1994).

Based on survey data, nutrition may be a concern for these communities, especially as it relates to obesity and chronic disease. Survey respondents reported frequent intake of high fat, high sugar, and low fibre foods. These results were similar to Sandy Lake, especially for Community C, which like Sandy Lake, is a large remote reserve. (Table 3.) Many elders noted the shift from traditional to store bought foods and the possible negative effects of this. Some pointed out that wild foods were traditionally boiled or roasted rather than fried, as is common today. Many teachers and parents also commented on the large amount of soft drinks, chips, and candy that children consumed. In Sandy Lake, similar concern over children's diet led to an Education Authority policy banning the consumption of chips and soft drinks in school.

Community A had the greatest concern surrounding obesity and lack of physical activity although these topics arose in the other communities as it related to diabetes. Respondents in community A did not always identify a connection between obesity and inactivity and diabetes. On all reserves people complained about lack of safe walking or exercise areas due to various concerns such as dusty roads, cars, and loose dogs.

At 53%, current rates of smoking on the reserves (Table 1) was higher than the 28% prevalence for the general Canadian population (Federal 1999), but this was not always perceived as a health problem. This rate is lower than the 67.9% found in Sandy Lake, but this may reflect secular trends since 1995 when the Sandy Lake data was collected. Enough people had quit smoking that it was generally not acceptable to smoke inside offices and many homes.

Although it was generally an acceptable pastime, a few respondents in community B viewed bingo as a negative gambling addiction:

> In my own opinion this community is cross-addicted. They put down the bottle, but some people picked up the [bingo] dabber or coins, put them into the machines. So you just, basically switched, in my opinion. So, it's also, maybe it seems a little more socially acceptable though, as opposed to the old days where [people were getting drunk].

Substance abuse was noted by participants to have declined drastically among older people. "...let's see, 20 years ago, 1980s, and late 70s…I'd say 95% of the community was drinking, so yeah, today I think it might be just the total opposite where 95% are alcohol-free or maybe just social drinking…" Alcohol was still a problem for some youth in the semi-remote communities A and B. In the remote community C where alcohol was prohibited, solvent abuse among some youth was a concern. "…there's lot of solvent abusers. Some have them have passed on through suicide, those kids that are solvent abusers, you know."

Mental health was another issue many people were working through. "Elders, my age, nowadays we experience a lot of negative feelings, like feeling negative, feeling depressed when we see what's happening to the families today…the breakdown of family structures." For many middle aged people their childhood experiences led to mental health and substance abuse from which they were still recovering: "We're starting to look at some

multi-generational issues, such as the residential schools, and the effects it has on our community. We need to do more work on that to understand the impact it has, on this generation, future generations."

One generational issue noted by some was a generation gap. They said that new ideas from younger people were often dismissed by older community members. This led to younger people avoiding getting involved in community activities. Elders complained that many traditions were not being passed on. They also lamented the breakdown of traditional family structures:

> It's true what I'm saying about families looked after their own children a long time ago. That was their responsibility. Today it's different. It's not like that. Children are being deserted left and right. Sure, parents today may think that they love their children. But then when it comes down to responsibilities, they don't show that. They would rather abandon their kids you know, from time to time, for whatever reason. Nowadays too many grandmothers are left to look after their grandchildren. It was never like that [before]. I took my children with me wherever I went. I never left them with anybody, I never left them with my mother.

Women were usually more interested than men in learning about health issues and issues concerning their children. They wanted to know more about nutrition and what to eat. Men and elders seemed to note more often the decline in their level of physical activity. A group of women suggested that this might be because many women still spent considerable time doing housework and walking places while men may use vehicles more and participate in sports less often than they used to. Several men also seemed more interested in broader issues on the reserves, such as housing, economic development, and healing, than in how to eat healthy or manage an illness. All groups were in agreement about the need to provide resources to children and to increase parental involvement in their education.

Finally, small size and remote location limited the resources for assistance. Access to care and patient-provider communication could be a problem in both remote and semi-

remote areas. This seemed to be less of a problem in the semi-remote area where the bands operated their own Health Access Center and faced less of a language barrier.

Availability of health and social services resources

As in Sandy Lake (Gittelsohn *et al.* 1994), community members may seek healthcare from both non-Native and traditional providers. In the Community A and B area where there are several small reserves, most health-related services have been transferred to the local Tribal Health Authority or directly to the bands. A First Nations and Inuit Health Branch (FNIHB) community health nurse still goes to some of the reserves once a week. A few of the bands have hired their own community health nurses to provide services beyond what the Medical Services nurses generally have time to provide. The local Tribal Health Authority oversees many programs. One of these is the Health Access Center in the nearby large town, where a physician and nurse practitioners provide primary care and referrals. The nurse practitioners also make community visits to the surrounding reserves. In addition the Center has health educators, a diabetes nurse educator, dietician, traditional healing coordinator, and various support staff.

Despite all these services, one provider in this area commented that there needed to be more emphasis on primary prevention of diabetes because medical intervention was often failing. She added that, "…diabetics need more time for teaching on glucose control, exercise, diet." There was a general sentiment among providers that individual and community level behavior changes needed to come have individual or community-level motivation in order to be successful, even if they were facilitated by outside healthcare resources.

Many of the existing programs focused on secondary prevention or treatment or were targeted at specific populations, but several of them have relevance to nutrition and physical activity. Because of the small size of the bands in the semi-remote region, provincial funding allocated by band size is sometimes consolidated by the Health Authority and delivered from the central Health Access Center rather than by each band. For instance, the Prenatal Nutrition Program (PNP) is administered by the dietician at the Health Access Center who makes regular visits to each community while the Healthy Babies, Healthy Children (HBHC) and Brighter Futures (BF) programs are run by local staff on each reserve. (Table 4.) In addition each reserve has a community health representative whose role may range from coordinating appointments and medical travel to actually overseeing programs.

In contrast, the large population and remoteness of community C resembles Sandy Lake more closely, where there is on reserve staff for many health programs. (Table 4.) A community physician comes to the reserve for about a week every month. The Sioux Lookout Diabetes Program provides screening, education, and counseling by diabetes nurse educators and dieticians in Sioux Lookout. Their staff also makes visits to Community C and other remote reserves (including Sandy Lake) about three times a year. All reserves also had a number of traditional healers who conducted ceremonies or made traditional medicines.

In all communities the schools had sought independent funding for nutrition related programs. Funding sources included Indian and Northern Affairs (INAC), The Canadian Living Foundation, and Dairy Farmers of Ontario. None of the schools had existing health curricula, and some did not have physical education instructors.

Although some people said they learned about diabetes from friends and family, lay people were not always recognized as a resource for information. Nevertheless, many of the diabetics in the community were well informed about their illness and proved to be good sources of knowledge.

Dealing with diabetes

What was most alarming for health providers about the diabetes epidemic was the apparent resignation or denial that people experienced with their diagnoses. This was a major barrier to maintaining blood glucose control and preventing complications. For many diabetics, keeping to their diet plan was the most difficult part of their illness. These issues may arise in part from the lack of awareness about diabetes that many community members commented on.

Some health providers felt that there was less surprise about diagnosis now. They noted that people appeared to accept it readily because diabetes had become so common. Some diabetics agreed that awareness and services had increased since their diagnosis. Other providers stated that although patients saw it as inevitable, they still struggled with denial or apathy towards self-care when first diagnosed. Most diabetics reported strong initial emotions to their diagnosis. These included: "...I accepted it.... But then again, I was neglecting for a while...in denial I guess...", " I freaked out...And then I was really angry, why am I [diabetic]?", "So I go to the doctor and he diagnosed that I was diabetic. So the first three months, I just drank my face off, I couldn't accept it, probably could have died."

In community A there was a sense of fatalism about diabetes that did not come through as strongly in the other communities. 50% of survey respondents in Community A agreed with the statement, "If my parents have diabetes, I will definitely get diabetes too." This

belief may be related to the high reported rates of diabetes and of parents with diabetes in this community. (Table 2.) A health care provider reported that many patients felt "doomed" by the diagnosis. Diabetics stated: "I knew I was going to get it anyway…I didn't really feel anything," and "…when I got diagnosed I felt like I was getting a life sentence or something, you know. And I was gonna be in that for the rest of my life, like I am, I will be." This view of diabetes did not preclude the ability to take action to manage the disease though. One diabetic said, "Once you get, diabetes in your system, you are in a death role, you can't, you can't change that…," but he also talked about finding his own way of treating the disease, which included taking oral hypoglycemics, controlling his diet, and seeking treatment from a traditional healer. Despite individual feelings of fatalism, overall 79% of respondents agreed that diabetes can be prevented in general.

Overall, 22% of survey respondents reported having diabetes. Many community members felt that diabetes was a major concern because they knew many people with diabetes, but knew little about the disease itself. Even people with diabetes admitted that they did not know much until they were diagnosed. For instance, one diabetic said, "I was never aware of the disease before I had it. I knew there were some people who were diabetics who were around. But I was not aware of the disease itself, until I got it." A non-diabetic expressed it this way: "Everybody knows we have a problem, but what are the symptoms? Like if students were to be informed as to, I don't know if you can protect yourself from diabetes or if it's hereditary, like I don't really know…." One recently diagnosed diabetic reported not seeking help despite having symptoms for several months and knowing that he was at high risk because of a strong family history of diabetes. When

asked what could be done to help prevent diabetes, a recurring answer was to increase awareness and have more workshops.

When asked about physical activity and diet, people expressed concern over children spending too much time watching television and eating too much "junk food." This was not necessarily associated with diabetes in their minds, but was seen as unhealthy. More often excessive consumption of sugar was associated with diabetes.

Diabetics also stressed that educating people without diabetes would not only help prevent diabetes, but it would give support to diabetics. In particular, they felt education for family members would be useful. One respondent reported, "So I was taught what not to eat, you know, not eat this, not eat that, stuff. So my wife never got anything like that, to be told what she should be feeding me.... I have to teach her that." One elder reported that it was sometimes difficult to follow her diet because other people cooked for her. Other diabetics commented on how it was helpful when their family members supported their diet changes and encouraged them to exercise. For some diabetics making these changes was the most difficult part of their illness:

> It's the diet, unh, what to eat, what not to eat. It's that when I am cooking for my family, that's what's hard for me. Because they're not diabetics yet,…because, what they eat, I usually don't eat what they eat, 'cause…And I'm the one that's cooking for them. That's what's hard.

Another respondent echoed this and made a suggestion:

> Another things should be done. When there's a diabetic in one household, I know they have foods and how they eat. I think the whole family should eat the same way. What the diabetic eats, it can be said. 'Cause when you see others, other kind of labels on food, you may want to go that way, in their way. But diabetic foods, I think that's the right way. Other families to follow what the diabetic eats. That way. That's why it's hard, when other, when other people eat different, because when they eat sweets, that's where I have a problem. I then want to eat the way they eat.

The way diabetic education was delivered was itself a concern for some diabetics. They reported that it was difficult to understand all the explanations they were getting about their

illness. One suggested, "…what I'd like to see myself provided to diabetics, is a diabetic dictionary. Like what is cholesterol, what does it really mean. Carbohydrates, those kind of things. It would be a little more simpler and easier for people to know what is talked about." Such terms were often used by health providers without patients understanding what they meant. In addition, it was often difficult to explain things to older family members in Ojibway. Sometimes there were no words in Ojibway for medical terms, or the appropriate translator was not available. Community members often felt they had limited access to culturally appropriate teaching materials.

Finally, health providers reported that proteinuria, and eventual renal failure, seemed to be one of the most common diabetic complications. For many family members this was the most visible, yet least understandable part of the diabetes course. They talked about the difficult decisions they had to make about complicated medical procedures and the eventual loss of the family member on dialysis. Another complication mentioned was cellulitis and related amputations. Among diabetics and people who had lost family members to renal failure or had amputations, these seemed to be strong concerns. Most other people had little knowledge about the complications of diabetes, and therefore not much specific concern.

Changes in concepts of healing and treatment

Elders noted that when they were young, few people became sick, and then it was only a cold or other minor illness that was treated with traditional medicines from the bush. Increases in chronic illnesses were often attributed to the major changes from traditional life over the past century. These included decreased activity, decreased intake of traditional foods and increased intake of fried or processed foods, or increased emotional stress from communal living and breakdown of traditional family structures. A few people mentioned

illnesses being caused by water polluted by industrial chemicals. These changes in illness patterns have been accompanied by changes in health-seeking patterns.

Older respondents recalled the changes in treatment:

> I never went to a doctor. I was always, medication though, my grandfather used to make them. And my mother used to make medicine for us when I was sick. That's why I never seen a doctor when I was little. That's how she raised us. I was just started to see the doctor just a little while ago ever since I lost my parents. And that's how we survived, didn't go to the doctor. Just used Indian medicine, for me anyhow.

Today, going to an allopathic healthcare provider is generally the first action in seeking healthcare, especially in semi-remote areas where they are more easily accessible. People also cited seeking additional information from books, magazines, pamphlets, the Internet, and occasionally friends or family. In addition, some people sought treatment from traditional healers, often at the same time as they were seeing an allopathic healthcare provider.

Two respondents commented on a change in attitude toward healing and how that affected health:

> All the health areas, like, usually if somebody doesn't feel good, they go to doctors, whether it's medical reason, or stress reason, or mental health issue, they all want to feel good instantly. Rather than work for, through that....they want that right now, feel better syndrome. When maybe you know if they did more of what used to be done…Something like, you know all the women used to get together and…Like ricing, you know, or traditional stuff. Crafts, whatever, and that's where they would talk. And talking is a form of counseling. And they'd get all that stress out. Where today it's, "Give me an aspirin, I've got a headache," rather than look at what's causing that. They just want to get rid of it. And I think that's why we're the way we are.

> …a lot of [our traditional] medicines come from the bush. And so now, too often it's too easy to go to the doctor, and get a prescription, get a pill, to be healed. You may be healed in the short term, but it always comes back. To go for healing in the traditional sense, in our own ways, it, it tends to work. When pills and other prescriptions are sometimes, Native people are highly addictive people, in my opinion. They get addicted to this way of thinking, this pill's gonna help and, this medication the doctor prescribes is gonna help you. But if you really think, if you take a good look at it from your traditional view, your Indian view …we have medicines that can cure anything, everything, but there's a certain protocol, certain method, a certain time to do these types things….So I always think of it in terms of prevention, if you do your traditional stuff, Indian names are important, your clan is important, communicating to each other through our Indian names, calling each other Indian names, because spirits are always around, always listening, and seeing how you live.

As discussed earlier, in community A there was a strong perception that diabetes ran in the family and may not be preventable. Acceptance of diabetes as inevitable did not always preclude taking action, although sometimes it led to a passive role of half-heartedly following providers directions, rather than taking active control of self-management. On the other reserves the increase in diabetes was primarily attributed to poor diet and decrease in activity. These causes were all mentioned in Sandy Lake as well. (Gittelsohn *et al.* 1994) Participants on all reserves agreed that in order to cope with the diabetes epidemic increased education and awareness were essential because even if people had heard of diabetes, they often did not know what they could do about it.

Adaptation of SLHDP interventions

Elements of SLHDP intervention components were both piloted and asked about in the survey. A school prevention program was overwhelmingly rated as the top choice by survey participants. Teachers and students exposed to the Sandy Lake curriculum gave very positive feedback.

Radio shows had the lowest overall relative rank, but placed second in Community C, which was the only reserve with its own community radio station. (Table 5) An audio drama on renal education originally intended for radio broadcast was played for groups on all reserves and was well received. Listeners found the information about renal failure useful and easy to understand in this story format. Some also appreciated that they were able to identify with the Native characters in the story. Renal education was second in the overall relative ranking. In Community C, where local access cable was available, a live television show on diabetes generated several calls and comments from community

members. Several community members suggested this communication method and radio as a good ways to reach a wide audience.

Although a grocery store intervention did not rank highly in Community C, testing of shelf labeling and concurrent flyer and radio promotion of 1% milk at a store resulted in much interest and steady sale of the specially ordered product. Two purchasers commented to the author that they tried the new product and found it acceptable. A demonstration of cooking methods and tips for healthier shopping at a large supermarket in a non-Native town serving Communities A and B and other semi-remote reserves did not reach a wide audience. Most customers who stopped to talk were either non-Native or Natives from the community where the researcher was residing and known to the researcher.

Home visits had a low relative rank, although a demonstration with a group of young women in Community A garnered positive responses. In the survey, younger women tended to rank this invention higher than men and older women.

Elders tended to prefer food store interventions or walking trails that they would be able to use. They were not as interested in the educational interventions, although sometimes this was because they thought they would not understand if they were in English.

DISCUSSION

The actual prevalence of diabetes among these communities is likely higher than the reported rate of 22% according to our survey. The excess can be attributed to the expected large number of people with diabetes who have yet to be diagnosed. In addition, Native populations usually have a younger age structure than the general Canadian population, which would result in an even higher age-adjusted rate. A prevalence of diabetes over 22%

and concerns about other chronic diseases in these three Native communities reflects the results from the First Nations and Inuit Health Regional Health Survey that found higher self-reported rates of diabetes, heart problems, cancer, and arthritis in aboriginals than the general Canadian population. (National Steering Committee for the First Nations and Inuit Regional Health Survey 1999) The reports on most common complications also reinforces previous literature showing that diabetes is the leading causes of non-traumatic lower extremity amputation (Reiber *et al.* 1995), and that Natives in Canada have a higher burden of end-stage renal disease, most of which is attributable to diabetes (Young *et al.* 1989).

Much of this excess burden of disease may be attributable to changes in diet and physical activity (Joint FAO/WHO Expert Consultation 2002;Storlien *et al.* 2000). Traditional Native foods such as wild game, fish, wild rice, and berries are lower in fat and simple sugars and higher in fiber than many of the foods frequently consumed on reserves today. People watch more television, and drive, rather than walk more often today. The increased concern with obesity in Community A may be a result of more readily apparent obesity in this community where access to fast food and vehicle ownership were more common than in Community C.

Many of the other health and social concerns raised by community members may be related to prevention and management of diabetes. For instance, maintenance of an active healthy lifestyle may be limited by other health concerns. One respondent told a story of a diabetic who continued to drink after his diagnosis, impairing his ability to take control of his illness. Depressed individuals are also less likely to take an interest in exercise and diet. Another respondent felt that she had learned to eat many unhealthy foods while in residential school. Separation from families meant that many children did not learn the

same parenting skills and healthy traditions of their parents. In families with limited income, a bingo addiction further reduces resources for healthy food and may leave older children responsible for feeding their siblings. Several respondents noted this interrelationship of health problems and the need to focus not only on individual behaviors, but on a healthy environment and a holistic attitude toward well-being.

As part of this environment, healthcare providers play an important role in increasing access to care and in educating patients about health and diabetes. As local resources familiar with each community, they will be important partners in future community-based prevention programs.

A limitation of our study sample is that we invited communities that expressed interest in a possible diabetes prevention project. This may have created a self-selection bias of communities with leaders who felt a need to address diabetes, and may not represent the situation in all Northwest Ontario reserves. This concern may have been associated with a higher prevalence of visible complications in their communities as compared to others that has alerted them to the problem. But based on information from health care providers who served several other communities in addition to those in the study, diabetes is a pressing issue in most Native communities. Communities not participating may simply have had many other equally pressing issues.

In planning the study we did solicit interest from a diverse set of study sites in order to maximize variation. We included both large and small, remote and semi-remote, and reserves from different treaty areas and tribal councils. The two semi-remote reserves had completed transfer of health care authority from FNIHB and were administering many of their own services and while the remote reserve just beginning the pre-transfer process.

Community C had completed transfer of education authority and managed its own school system, while the other reserves utilized non-Native public schools.

Although diabetes was a concern in all communities, these kinds of differences between communities are important to note in planning appropriate interventions. Unemployment and the high cost of groceries, especially fresh produce, were a complaint on all reserves, but the limitations were more extreme in the remote location. There was greater emphasis on Native language in education in the remote settings, and more physical activity. Many people still walked around the reserve and participated in sports or activities such as fishing, hunting, or collecting firewood. Therefore program components may need to be modified to suit each reserve. For instance, without community radio listener ship in the semi-remote reserves, a mass media intervention may have to rely on newsletters, pamphlets, and posters. In general, results from this study are similar to those found in Sandy Lake, although Community C may be most like Sandy Lake due to similar characteristics related to remote location and large size.

The results of the study indicate that great social changes have had a large impact on Native lifestyles. Changes in residential patterns, increases in technology, and new sources of livelihood have resulted in decreases in activity levels. At the same time, food sources have increased, but not always with improved nutritional value. Limited economic opportunity and high costs associated with remote location contribute to difficulty in accessing healthy foods. Although costs for produce and many other products were higher than in major urban areas, observation of stores revealed many equally priced healthier products available. Unfortunately 59.4% of respondents agreed with the statement, "It costs more to eat healthy." Survey data revealed many areas where equally priced alternatives

could improve nutritional value. For instance, wheat bread could be substituted for white bread at equal cost. (Table 3.)

Based on these findings and piloting experiences, it is most likely that a combination of a school-based, store-based, and mass media programs would reach the largest audience and be the most acceptable and sustainable for similar Native communities in Northwest Ontario. Despite the differences between each of the communities, self-determination, and community input into an appropriate intervention were noted to be essential in the success of an intervention. The continued interest of these communities in further research demonstrates the success of an approach that engages community members in examining their own needs and resources.

The dearth of community-wide diabetes prevention programs and the articulated need by community members for increased awareness reiterate researchers calls for increased prevention efforts (Daniel and Gamble 1995;2003). Therefore, we propose that a community-based program including educational and environmental changes could help community members make cost-effective healthier food choices and increase activity levels.

CONCLUSIONS

There is ample need and desire from Native communities to address the diabetes epidemic in their midst. The many psychosocial, cultural, environmental, and economic issues affecting risk factors for diabetes require a broad-based participatory approach to prevention efforts. To address this, a multi-site community-based intervention trial is being planned in collaboration with a clinical prevention trial. The community-based intervention will consist of three components promoting healthy lifestyles: a school-based program, a

food store program, and a mass media program. Several communities have already attended a planning meeting and submitted letters of collaboration pledging their participation.

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Table 1: Methods

Method	Number of People[1]	Types of participants
Interviews: semi-structured in depth interviews	81	Adult community members, health care providers, school and food store staff
Observation: informal direct	>190	Students in class, lunch, recess, stores
Group Activities: seasonal calendars, voting, mapping, problem tree, venn diagrams, discussion, etc.	143	Community members
Demonstrations: School lessons, cooking, slide show, radio/TV call-in programs, home visit, etc.	N/A	Community members
Survey: on risk factors and attitudes	72	Randomly selected band members over 18 living on reserve

Table 2: Frequency of selected risk factors of survey participants

	A (n=28)	**B (n=19)**	**C (n=25)**	**A+B+C (n=72)**	**Sandy Lake (n=527)**
Average age	40.63	38.21	36.67	38.7	35.7
% female	51.9%	73.68%	60.0%	61.1%	56.67%
% speaking fluent Ojibway	78.57%	21.05%	40.00%	50.0%	N/A
Reported diabetes diagnosis	28.6%	15.8%	20.0%	22.22%	17.2%**
Report one or more parent with diabetes*	71.4%	26.3%	72.0%	59.72%	N/A
Report one of more siblings with diabetes	50.0%	10.5%	52.0%	40.0%	N/A
Current smokers	57.1%	47.4%	52.0%	52.78%	67.9%
3 or more	39.3%	58.0%	36.0%	40.28%	34.3%

hours of television viewed per day					

*approximately 25% of respondents did not know whether one or both parents had diabetes or not.
** prevalence based on screening of persons 10 years and older. Age-adjusted prevalence was 26.1%. Sandy Lake data is based on a survey conducted between July 1993 and March 1995.

Table 3: Selected food intake frequency of survey participants

	A (N=28)	**B (N=19)**	**C (N=25)**	**A+B+C (N=72)**	**Sandy Lake (N=525)**
Margarine > once a day	46.5%	52.6%	68.0%	55.55%	51.2%
Bacon or pork chops > once a week	50.0%	53.0%	76.0%	59.72%	80.0%
Fast food > once a week	57.2%	63.2%	24.0%	47.22%	N/A
White bread > once a day	42.9%	42.1%	76.0%	54.16%	78.9%
Eggs > 3x a week	64.3%	47.4%	88.0%	68.06%	67.2%
Regular soda > once a day	21.5%	47.4%	33.3%	32.86%	N/A
Diet soda > once a day	10.7%	15.8%	12.0%	12.50%	N/A
Potato chips > once a day	14.3%	21.1%	20.0%	18.06%	15.5%
Fresh fruit from the store > 3x a week	53.6%	73.8%	44.0%	56.94%	54.5%
Chocolate/candy > 3x a week	14.2%	33.4%	25.0%	22.86%	17.1%

Table 4: Access to health or social services staff by reserve

Health or social service staff	Community A	Community B	Community C	Sandy Lake
Community Health Representative	On reserve	On reserve	On reserve	On reserve
Community health nurses	Off reserve	Off reserve	On reserve	On reserve
Full-time physician	Off reserve	Off reserve	Off reserve	Off reserve
Prenatal Nutrition Program	Off reserve	Off reserve	On reserve	On reserve
Home and Community Care Program (for homebound or recently hospitalized clients)	Off reserve	Off reserve	On reserve	On reserve
Healthy Babies, Healthy Children (0-6 yrs.)	On reserve	On reserve	On reserve	On reserve
Brighter Futures (youth)	On reserve	On reserve	On reserve	On reserve
Aboriginal Diabetes Initiative/Diabetes Program	Off reserve	Off reserve	On/Off reserve	On/Off reserve
National Native Alcohol and Drug Abuse Program	On reserve	On reserve	On reserve	On reserve
Mental health counseling	Off reserve	Off reserve	On reserve	On reserve
Traditional healers	On reserve	On reserve	On reserve	On reserve

Table 5: Relative mean ranking of potential intervention strategies

Intervention	A (n=28)	B (n=19)	C(n=26)	A+B+C (n=72)
School health curriculum	1	1	1	1
Renal education	2	3	4	2
Pamphlets	3	5	3	3
Grocery store	5	2	6	4
Home Visits	4	3	5	5
Radio shows	6	6	2	6

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