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Serious Complications for Patients, Care Providers and Policy Makers: Tackling the Structural Violence of First Nations People Living with Diabetes in Canada

Marion A. Maar Dr.

Northern Ontario School of Medicine, Marion.Maar@nosm.ca

Darrel Manitowabi

University of Sudbury, dmanitowabi@usudbury.ca

Danusia Gzik

Northern Ontario School of Medicine, dgzik@hotmail.com

Lorrilee McGregor

Laurentian University, communitybasedresearch@hotmail.com

Cheri Corbiere

cheri.corbiere@sympatico.ca

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Abstract

Type 2 diabetes mellitus is a progressive metabolic disorder that affects Aboriginal people disproportionately around the world. Evidence shows that diabetes treatment strategies can effectively reduce complications related to the disease; in contrast many Aboriginal people develop these rapidly and at a young age. We conducted qualitative research on the barriers to evidence-based self-management behaviours and education from the perspectives of Aboriginal people living with type 2 diabetes and their health care providers on Manitoulin Island in Ontario, Canada. Applying the concept of structural violence, we analyzed the social and political arrangements that can put Aboriginal people with diabetes “in harm’s way” by interfering with diabetes management. Lastly, we provide recommendations for structural interventions.

Keywords

Diabetes, Aboriginal people, social determinants, structural violence

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The lived experience of diabetes

I had just heard about sugar diabetes. ... Next thing I knew, I had it. I had it bad! My numbers were 23 – 28 (high levels of blood sugar). Now I'm borderline – so they say. My doctors check my numbers every week. Now I eat like a rabbit. (Zoozep, Elder)

Nine years ago I was told I had diabetes. My diabetes nearly took me away a couple of times. I had convulsions. My sugar was way out of whack. I didn't know anything about it. Now, today, I keep track of my sugar levels, and I had to do away with a lot of mijjim (food) that I used to eat. (Bienh, Elder)

Introduction

Type 2 diabetes affects many Indigenous populations worldwide at disproportionately high rates compared with their mainstream counterparts (Carrasco et al., 2004; Daniel, Rowley, McDermott, Mylvaganam, & O'Dea, 1999; Davis, McAullay, Davis, & Bruce, 2007; Roberts, Jiles, Mokdad, Beckles, & Rios-Burrows, 2009; Yu & Zinman, 2007). In Canada, Aboriginal populations have diabetes rates 3 to 5 times higher than the general population, develop diabetes earlier in life, experience more rapid onset of diabetes-related complications, and suffer poorer treatment outcomes (Dannenbaum, Kuzmina, Lejeune, Torrie, & Gangbe, 2008; Dyck & Tan, 1994; Hanley et al., 2005; Young TK, Reading J, Elias B, & O'Neill JD, 2000).

According to evidence based clinical practice guidelines, optimal diabetes management can help to “control” the disease and significantly reduce the onset and severity of complications. The chronic disease management model underlying the Canadian clinical guidelines necessitates substantial health literacy and daily self-management by the patient in order to effectively prevent or delay complications (Canadian Diabetes Association Clinical Practice Guidelines Expert Committee [CDACPGEC], 2008). In this paper we explore the underlying socio-political factors that may interfere with effective diabetes care in Aboriginal communities. Drawing on the concept of structural violence, we analyzed the social and political arrangements that can put Aboriginal people with diabetes “in harm’s way” (Farmer et al. 2006, pg. 1686), by interfering with the key components of healthy diabetes self-management behaviors and self-management education.

To accomplish this, we conducted qualitative research on the perceived social determinants that create barriers to evidence-based self-management behaviours from the perspective of Aboriginal people living with type 2 diabetes and their health care providers on Manitoulin Island, in north central Ontario, Canada. Our intent is to initiate a discussion of socio-political forces, which are largely beyond the control of individual patients but impact management of diabetes. Furthermore, we recommend immediate structural interventions that may ameliorate the current health inequity of premature disability and death resulting from type 2 diabetes in Aboriginal people.

Diabetes and Aboriginal People

Type 2 diabetes is a serious progressive metabolic disorder characterized by elevated levels of blood glucose. Rates of type 2 diabetes are increasing globally, despite the fact that it is a largely preventable disease.

For many people, type 2 diabetes leads to serious complications, such as blindness, heart disease, kidney problems, nerve damage and erectile dysfunction, and the risk of complications increases with disease duration. However, research shows that evidence-based diabetes management can be highly effective: People can live healthy and productive lives if they are able to control glycemic levels, blood pressure, and lipid and stress levels, through careful self-management strategies combined with optimal clinical care (CDACPGEC, 2008; Gaede, Lund-Andersen, Parving, & Pedersen, 2008; Holman, Paul, Bethel, Matthews, & Neil, 2008; Patel et al., 2007; Stratton et al., 2000; UK Prospective Diabetes Study (UKPDS) Group, 1998). However, diabetes care is complex. It is comprised of a combination of clinical monitoring, using tests and prescriptions, with self-management of medications, diet, physical activity, smoking cessation and self-monitoring of blood glucose (see Table 2). Often, patients struggle to adhere to their management plan, and this is pronounced for those with depression (approximately 25%) (CDACPGEC, 2008).

Although Aboriginals have high rates of type 2 diabetes and poor treatment outcomes relative to non-Aboriginals across the globe, much research has focused on elusive, racially-based, genetic models to explain this inequality (for a review see (Fee, 2006; Poudrier, 2007)) as well as culture and modifiable behavioral risk factors (for example: (Aluli et al., 2009; Harjo, Perez, Lopez, & Wong, 2011; Ley et al., 2009; Ley et al., 2011; Nsiah-Kumi et al., 2010; Oster & Toth, 2009; Wang, Hoy, & Si, 2010).

The predominant individual-focused approaches have not led to significant improvements in diabetes management; instead, they tend to emphasize the role of patients and blame them for their health outcomes. For example, although not a commonly shared belief in our study population, one care provider stated: "Nowadays everyone needs a personal trainer and a dietetic cook [to engage in a healthy lifestyle]. People should just take responsibility for their own health!"

Structural Violence

Using a social determinants of health lens, the lack of improved outcomes is not surprising since "*inequities in health ... arise because of the circumstances in which people grow, live, work, and age, and the systems put in place to deal with illness*" (Commission on Social Determinants of Health [CSDH], 2008). Genetic and behavioural risk factor approaches are limited because they ignore the significant impact of external conditions and circumstances on the progression of the illness.

More critically oriented research explores the *circumstances* in which many Aboriginal people grow, live and survive. These circumstances include the legacy of Canadian colonial practices such as enforced dietary and lifestyle changes on reserves and in residential schools, socio-economic disparities, exposure to racism, and marginalization of Aboriginal issues. These issues are all important determinants of chronic diseases, such as diabetes. (Manitowabi & Maar, 2011; Reading, 2009; Richmond & Ross, 2009; Royal Commission on Aboriginal Peoples[RCAP],

1996; Waldram, Herring, & Young, 2006). However, little research has focused on how socio-political processes influence the progression of chronic diseases by affecting conditions under which Aboriginal patients must self-manage the disease.

Farmer and colleagues (2006; cf. Farmer 2004, 2005) have examined the connection between health care and socio-political factors such as poverty and inequality. They observe an increasing “desocialization” of health issues in contemporary health discourse and boldly ask, “Does our clinical practice acknowledge what we already know—namely, that social and environmental forces limit the effectiveness of our treatments (1686)?” Farmer et al. use the concept of structural violence to pinpoint the political and economic configuration of our social world that “put people in harm’s way”, leading to disproportionately negative health outcomes for marginalized populations (ibid.).

Farmer, a physician and anthropologist, acknowledges that medical professionals are not normally trained to understand or confront structural violence, although it interferes with access and adherence to treatment. In order to overcome structural violence in clinical care, it is necessary to work on multiple interventions, including proximal (preventing illness) and distal (when people are already ill) components (ibid.). In what follows, we identify the structural barriers that can affect access and adherence to self-management and conclude with recommendations for structural interventions to address these barriers.

Methodology

This research is part of a larger study, the Manitoulin First Nations Diabetes Care and Prevention Research Project, initiated in 2005 through a partnership developed between university based researchers, six First Nations communities, and the three health boards affiliated with the local First Nations political organization, the United Chiefs and Councils of Mnidoo Mnisising (UCCMM). The long-term goal of this project is to improve the effectiveness of First Nations diabetes prevention programs and diabetes care through participatory action research (Maar, Gzik, & Larose, 2010; Manitowabi & Maar, 2011).

This qualitative research incorporated 13 focus groups with 76 participants consisting of sessions with health care providers, elders, and community members with diabetes (see Table 1). Using Grounded Theory Methodology, we asked participants’ perceptions of factors that affect diabetes care. Focus group questions included perceptions of local diabetes care, opportunities/barriers for healthy lifestyles, and lived experiences of diabetes. Questions were adjusted for each session to correspond to the following: a) the experience and expertise of each group; b) our growing understanding of barriers; and c) to triangulate or disconfirm evidence. Sessions were audio-recorded and aliases were assigned; in several cases audio-recording was seen as inappropriate and two researchers took notes that were compared and consolidated. A translator was present for the sessions with elders to allow them to speak in either English or Ojibwe.

Consistent with the spirit of participatory research, all parts of this study were based on interdisciplinary collaboration. Sessions were transcribed and university and community-based researchers thematically analyzed the data independently. Divergent results were consolidated through discussions. Rigor was further enhanced through peer review and member checks with a community-based steering committee. Finally, themes were mapped on recent evidence-based self-management behaviours (Table 2) and diabetes self-management education.

Results and Discussion

Participants discussed determinants they perceived to interfere with many Aboriginal peoples' ability to implement diabetes self-management. Thematically, the determinants fell into categories of barriers to self-management education, healthy diet, physical activity, and self-efficacy to become proficient at self-care in general. These barriers are illustrated through the voices of participants and situated within the context of existing research in the next section.

Barriers to Self-Management Education

Diabetes education must support self-management through approaches that promote informed, independent decisions relating to the individual's diabetes management (CDACPGEC, 2008 p. S20).

Language. Participants explained that language and cultural barriers were significant for some elders as well as some others, who, although they may be able to communicate in English, have great difficulties understanding or asking questions about their treatment plan. Elders explained that diabetes education in their language (Ojibwe), tailored to their individual and cultural backgrounds, provided by lay educators in First Nations health centres, is very important for their learning about diabetes management:

The family has to learn what diabetes is. You have to explain why you can't eat certain foods. [Diabetes lay educator, who teaches in the local language] used to come around... He had actual things that show how diabetes works – he had a [model of a] foot to show amputations. Actually seeing stuff helps. And it's amazing how much salt you're actually taking in. He showed me that too. [Learning from him] it strengthened my conviction that I was diabetic. I have to do the work – no one can make me. Today, I live with it. I watch what I eat. I see people stacking up their plate. That's not how I eat. Years ago we had a good breakfast, lunch was the main meal, and supper was a bowl of soup. Nowadays we have a big meal late in the evening. It just sits in your stomach then you go to bed...It is hard, you have to be dedicated...I pray to get through the day without eating [too much].

Health literacy. The ability to obtain and use health information and services to make appropriate healthy decisions is influenced by language and requires a culturally appropriate approach to health education. Elder *Maanii* told the story of being diagnosed with symptoms of prediabetes in the doctor's office. Prediabetes screening is important since the onset of diabetes can be prevented at this stage if health education and lifestyle changes can be implemented. Lacking appropriate health knowledge about prediabetes, she took a health-threatening course of action:

When I was told that I was "borderline" diabetic I ate all the bad foods like ice cream that I could. Because I thought that once I have diabetes I won't be able to eat any of this food.

Another elder, *Jenyep*, had a similar story:

I didn't know anything about diabetes or high blood pressure until recently. I don't know much now. I'm sorry that I didn't learn it.

These are not isolated examples. Care providers spoke of many patients with harmful misconceptions or inexperience with the disease. Elder *Pillup* was said to have made an appointment to treat a serious diabetic foot ulcer but was surprised to learn that the ulcer was related to diabetes. He remembered once being diagnosed with diabetes but he thought that his illness “had gone away by now”. Furthermore, patients commonly resist insulin treatment because they believe it causes serious complications like amputations or even death, although from the biomedical perspective it may actually prevent these complications by stabilizing blood glucose levels. A common sentiment health providers encounter is: “*I don't want to go on insulin – My aunt went on insulin and two years later she died*”.

Cultural safety. Several participants explained that some Aboriginal patients face cultural barriers communicating with some of the non-Aboriginal health care providers. *Besah*, an elder, told the following story of being diagnosed with diabetes. The disconnect with his provider resulted in non-adherence to a treatment plan and subsequent need to initiate antihyperglycemic medications:

I've been a diabetic for 30 years. I found out when I was in the hospital from a blood test. My bed was opposite the nurse's station. I heard the doctor talking about me. He said with proper diet and exercise that I wouldn't get diabetes [related complications]. I didn't experience the list of symptoms [of diabetes]. I was too busy. I didn't do what [the doctor] said. Next thing what happened I had to take pills. Then he showed me how to do insulin needles... I had to do something – I couldn't go on the way I'd been going.

A holistic culturally based approach was seen as an effective way of teaching by all:

I attended a workshop on diabetes – and the teachings were presented by [a First Nations health provider and respected elder]. She shared a holistic view of eating, based on the medicine wheel. There are many teachings in that medicine wheel. (Maaniyan, Elder)

On the flipside, lack of a holistic approach was seen as harmful to diabetes self-management:

Lack of the medicine wheel and spirituality affect people [living with diabetes]. A lot of people left the church and the traditional ways... but it was not replaced by anything. And what about stress? There is a lot of that today. There is no time to take time out for yourself. There used to be a lot of camps, like maple sugar... that was time out with yourself and nature. That kind of meditation is missing [today]. We have to start from the Anishnaabe way, we have to thank the creator, and everything flows from there. We need to teach our young people. The sacredness is how we should begin. (Esta, Elder)

Many participants emphasized the relationship between spirituality and holistic approaches to health in diabetes self-management. Their sentiment is in line with previous research: First Nations in the Manitoulin area have identified service provider acceptance of religions, spirituality, traditional beliefs, knowledge of Aboriginal history, understanding of life on

reserve, and building on the existing strengths of Aboriginal people and their communities as key components of culturally safe services (Maar et al., 2009; Maar & Shawande, 2010). Clearly, many Aboriginal people with diabetes require ongoing culturally congruent education to acquire the tools, skills and supports they need to effectively self-manage diabetes. Improvements to the cultural aspects of health care are definitely necessary, with cultural safety an important concept to advance within the health care system in order to enhance effectiveness of services and health literacy among Aboriginal patients with diabetes.

Barriers to a Healthy Diet and Nutrition

Nutrition therapy can reduce glycated hemoglobin by 1.0 to 2.0%. Replacing high-glycemic index carbohydrates with low glycemic index carbohydrates in mixed meals has a clinically significant effect on glycemic control in people with type 1 or type 2 diabetes. (CDACPGEC, 2008, p. S40)

Food insecurity is one area that participants believed impacted diabetic patients' ability to engage in healthy "choices" such as eating lean meats, fruits, vegetables and whole grain products. Many of the healthier food options are expensive and inaccessible to some people living on reserve in poverty. We also heard from care providers that some diabetic patients run out of food completely between cheques:

People on social assistance don't have money to buy fruits and vegetables in the last week or two [before they receive their monthly assistance]. For them, it's a feast and famine way of life. They eat really good [sic] during the first two weeks. Then they have very little. One of my clients always has high blood sugars after he gets his cheque but later in the month it gets lower.

The period of time spent with little food is just as much of a health risk as the period characterized as "feasting". Fasting can lead to dangerously low blood glucose levels and result in seizures and diabetic coma for patients on antihyperglycemic medications (CDACPGEC, 2008).

The distance to large grocery stores is considerable for many Aboriginal people living on reserve, and the cost for transportation can take up a significant portion of their food budget. For some, travel to grocery stores is not an affordable option; therefore, food has to be purchased from local variety stores, which are heavily stocked with high-calorie, high-glycemic, nutrient-poor foods that are not good choices for the optimal nutrition therapy aspect of self-management.

Barriers to Physical Activity

Moderate to high levels of physical activity and cardiorespiratory fitness are associated with substantial reductions in morbidity and mortality in both men and women and in both type 1 and type 2 diabetes (CDACPGEC, 2008, p. S37).

Poverty at the individual and community level impedes many people's ability to engage in medically required physical activity. Exercise equipment, gym membership or participation in organized sports is simply not affordable to many First Nations patients. While arguably one of

the cheapest yet effective forms of activity is brisk walking, this form of exercise is often hindered by the poor state of the reserve roads and infrastructure. Walking on roads can be dangerous in the winter months as ice and snow make walking treacherous for people with mobility difficulties related to the progression of diabetes. Additional safety concerns included poor visibility due to lack of street lighting, insufficient policing and lack of animal control services to address semi feral dogs or bears that threaten walkers on some reserves.

Evidence shows that in the early stages of diabetes, glycemic levels can be controlled by self-managing nutrition and exercise; however, on Manitoulin Island, First Nations patients are significantly less likely than Euro-Canadians to succeed in managing diabetes through lifestyle alone (Maar, et al., 2010). Given the many influences of poverty induced interference with self-management outlined above, this is not surprising. Poverty and diabetes have also been shown to be connected empirically. Using epidemiologic data from the Canadian Community Health Survey, researchers have demonstrated that diabetes is 4.14 times more common among low income Canadians. Income remains independently associated with the risk of developing type 2 diabetes even when individual risk factors were accounted for, including obesity (Dinca-Panaitescu et al., 2010). The systematic underinvestment in First Nations infrastructure and the economic disparities at the community level are clearly impeding diabetes self-management in numerous ways, including nutrition and exercise.

Systemic Multi-generational Barriers to all Aspects of Self-Management

Participants identified the existence of systemic barriers manifested as mental health and addictions issues, but rooted in multigenerational trauma of past and present socio-political processes. These barriers interfere with people's ability to acquire the self-efficacy to master self-management.

Mental, emotional and spiritual "un-wellness". Mental health issues related to diabetes occur in all populations; however, care providers revealed an urgent need for mental, emotional and spiritual support for First Nations people with diabetes for various reasons. Rampant uncontrolled diabetes exists in many Aboriginal communities and results in the rapid deterioration of the health of some people. Consequently, many patients believe the diagnosis is a death sentence as they have lost family members or know others who have experienced amputations. A mental health worker explained: *"They think 'that could be me!' Their focus becomes directed at that and that results in a lot of depression, anxiety and resurfacing of old trauma"*. This sentiment was confirmed by a distraught patient:

My family did not have diabetes, now I have it! Why? I wasn't a heavy drinker, I eat fairly well. I am not overweight. I have not smoked for 30 years. Why do I have it?I hope they find a cure for diabetes someday! Soon before we die from it. Losing your body parts, your limbs...that is scary! (Maganiit, Elder)

Another mental health worker explained the relationship between addictions, mental health and diabetes:

If clients are dealing with substance abuse then we know it is impacting heavily on their ability to deal with diabetes. Addictions are a pretty obvious factor that impacts [on diabetes management]; having a mental health problem of any sort interferes with taking care of diabetes; it interferes with people's motivation to pursue a healthy lifestyle. If they are depressed they don't have the energy or motivation to go change their lifestyle, to start walking or interact socially. They will experience some degree of difficulty in taking care of themselves.

A fourth worker put it this way: *"Having diabetes – it is not curable – you have it for the rest of your life – that depresses you – managing all of that is the challenge". Pichi, an elder with diabetes shared her perspective: "It is hard to accept this diabetes, it makes me feel depressed to have it; I never wanted to have this!"*

Medical research strongly agrees with the views expressed in focus groups: depression, and diabetes are closely linked to each other, and depression may even accelerate the onset of diabetes-related complications in diabetic patients (Musselman, Betan, Larsen, & Phillips, 2003). Despite the fact that research, care providers and patients agree that there is a need for mental and emotional support services, few of these services are accessible on reserve:

The approach has been to address the physical side of diabetes – the focus has always been to manage your diet and your physical activity – the emotional side never gets identified or prioritized – that in itself is a barrier. The first response in a client to diagnosis is usually the trauma – but in general, the overall approach is just to manage as if the physical is the only side of it (fourth mental health worker).

First Nation mental health services are scarce despite the documented high need for these services (Health Canada, 2006; Kirmayer et al., 2007; Kirmayer, Brass, & Tait, 2000; Kirmayer & Guthrie Valaskakis, 2009; Wesley-Esquimaux & Smolewski, 2004; Wieman, 2006). Health Canada's First Nations and Inuit Health Branch (FNIHB) provides modest alcohol and addictions programs consisting mainly of paraprofessional workers and short-term crisis intervention therapy. These services are utterly inadequate to deal with the complexity of mental health issues in First Nations, creating serious gaps in services for those people who need them. Consequently, crises related to mental health, addictions and suicide are relatively common. Even in communities that have successfully managed to leverage alternative funding for mental health services, the mental health staff typically carry a high case load of urgent or crisis care clients, taking priority over diabetes management supportive services. Therefore, the mental and emotional needs of diabetic patients are rarely addressed. Traditional Aboriginal wellness approaches to diabetes were often discussed as being beneficial to the overall well-being of patients, including their mental and emotional health:

Spirituality is to each their own, but we need Gchimnidoo (the Great Spirit) in our lives. You should give thanks every morning and at night give thanks for the day. It helps me and I feel really good about it. (Maaniyan, Elder)

The holistic approach of traditional medicine seeks a balanced physical, mental, emotional and spiritual lifestyle with an emphasis on self-care. It is, at face value, congruent with evidence-based approaches to diabetes. However, due to historic assimilation policies, some

Aboriginal people are ambivalent toward traditional medicine. Participants described a wide range of divergent experiences. Elder *Maatii* explained: “*we didn’t grow up that way*”. But many participants recalled that traditional medicine was part of their grandparents lives (translated from Ojibwe):

My grandfather made a medicine [for diabetes] – like a blood purifier – and you couldn’t eat sugar, salt, alcohol, and coffee. He taught it [to a local traditional healer]. If you don’t pick those medicines, they don’t grow anymore. You have to thank the spirit of the plant. You have to keep picking strawberries – otherwise the plant will give up (become less plentiful). My grandfather used to say to put tobacco down for the plants otherwise they get angry. (Aanzhenii, Elder)

Another elder, *Aanzhen*, confirmed that traditional ways have been resilient and irrepressible in the Manitoulin region:

My grandparents were devout Catholics – they were the caretakers of the church and they also fed the priest. But they also practiced traditional medicine without the priest’s knowledge.

Elders explained further that holistic traditional Aboriginal approaches were the norm within their lifetime in local communities, before residential schools and other influences discouraged their use. Today, however, some patients are not comfortable with traditional approaches. Health care providers explained that some Aboriginal patients do not seek traditional medicine “*until it is too late*”, for example, at the onset of severe complications such as renal failure. A greater emphasis on de-colonizing these traditional approaches is necessary to encourage a holistic approach to healthy living.

Colonialism and Multigenerational trauma. Many health care providers recognized that they had a significant number of Aboriginal patients who are dealing with consuming issues in their lives and, despite the serious nature of the disease, diabetes self-management was not a priority. They discussed that some patients have good management knowledge but still experience overwhelming barriers, such as current or past, unresolved physical or sexual abuse issues, or, violence or addictions within their families:

[These patients] know what they need to do – but they cannot identify what stops them from acting – they know they must exercise, watch their diet, and take their medications but sometimes perhaps due to their busy lifestyles, or problems in the extended family or preexisting social issues are blocking them so they cannot make [self-management] a priority. (physician)

Some of these patients may have internalized a self-destructive attitude towards their care and are unable to make chronic illness management a priority. In addition social and family issues can take precedence over a focus on personal self-care, as some patients embody the belief that “*everybody else is higher on my priorities*” or even believe that they are undeserving of a good life. Some Aboriginal participants clearly linked this perspective with their attendance at residential schools:

The residential school brainwashed you into thinking your culture was not good and not to practice your beliefs. The residential school apologized for what they did. The bishop finally confessed to all the residential school delegates. We were there 8 days [meeting at the site of the school]. Some couldn't go to the podium – they got too emotional... they had been punished and now some can't speak their native language. It took me 15 years to get my language back. (Miigwans, Elder)

The multigenerational causes of high rates of mental health issues, such as mood disorders and addictions, and violence and abuse histories, observed in many Aboriginal communities, as well as the effects of colonial disempowerment, racism, marginalization and the residential school system, have been well documented in the literature (Brave Heart & De Bruyn, 1998). These issues, combined with everyday stresses experienced by people on reserve, coupled with the stress of living with a chronic disease, was believed to impact heavily on Aboriginal people with diabetes:

Life is stressful. I was talking to someone about diabetes. He was told to take his blood test every morning but he just did it once per month. It was too stressful to do every day. (Zhaabadiis, Elder)

Zhaabadiis, further explained that by itself poor blood glucose values cause stress for people. Similarly, negative stressors for Aboriginal people with diabetes have been shown to include difficulty of managing diabetes; marginal economic conditions; trauma and violence; and “cultural, historical, and political aspects linked to the identity of being Aboriginal” (Iwasaki, Bartlett, & O'Neil, 2004, p.189). Related themes emerged in our focus groups. Medical research shows that psychological stress has direct and indirect negative influences on diabetes: first, it has a physiological response that raises blood glucose levels; second, it makes it more difficult for patients to adhere to a treatment plan. Together, these influence the risk of complications significantly (CDACPGEC, 2008).

A further expression of multigenerational trauma is arguably the internalization and acceptance of the racially-oriented research that problematizes Aboriginal biology. For example, one youth participant exclaimed: “*If diabetes is genetic, I am screwed!*” This fatalism towards diabetes is linked to a hypothesized genetic predisposition in Aboriginal people popularized by the media and in some health literature. Ironically, while largely discredited in academic circles (Fee, 2006) and recently even in the media (Abraham 2011), it is commonly accepted among participating community members as well as care providers, negatively impacting on the self-efficacy required for self-management.

In summary we found that colonialism, multigenerational trauma and the related high levels of mental and emotional “un-wellness” in Aboriginal communities interferes with many patients’ self-efficacy to manage a complex disease such as diabetes. These significant challenges, combined with a lack of healing services to address these issues, restricts patients’ psychosocial ability to regain the necessary balance in their lives to self-manage their disease.

Conclusions

While they readily acknowledged that some of their Aboriginal patients are doing very well managing their illness, health care providers in this study were in agreement that they see, on average, poorer outcomes for Aboriginal patients with diabetes compared to non-Aboriginal patients. This sentiment has since been empirically confirmed with a medical chart review (Maar, et al., 2010). Complications are closely linked to the inability to achieve self-management. One primary care provider with a biomedical perspective comments:

Compliance [to a treatment plan] is the big issue, there seems to be a big contrast between the non –Aboriginal population and Aboriginal populations regarding how they gain control of diabetes; among the Aboriginal Populations there seems to be more of a lack of control [of diabetes] due to compliance issues.

It is important to look beyond the surface and identify the root causes of non-adherence, to prevent the unjustifiable blaming of socio-politically disadvantaged and vulnerable patients for their deteriorating health. Given the significant barriers to evidence-based self-management experienced by many Aboriginal patients, adherence to a treatment plan is indeed difficult to achieve.

The Social Violence of Diabetes Related Complications

We set out to examine “the social and political arrangements that can put Aboriginal people with diabetes ‘in harm’s way’ by interfering with the key components of healthy diabetes self-management behaviors, and its prerequisite of self-management education.” The connections with the tenets of structural violence and our research are compelling. We have shown that First Nations economic, social and political marginalization can create barriers for Aboriginal patients with diabetes with respect to the following: a) culturally safe self-management education; b) dietary self-management ; c) physical activities self-management; and (d) self-efficacy required for chronic illness self-management in general. These barriers put people with diabetes in harm’s way by interfering with evidence-based diabetes care, ultimately increasing the risk of rapid onset of complications. Our research supports the World health Organization’s assertion that the “*persistent inequity in the health conditions of Indigenous populations goes to the heart of the relationship between health and power, social participation, and empowerment*” (CSDH, 2008). The determinants of poor diabetic management uncovered in this research are inseparable from the structural violence exhibited in colonial history resulting in persistent disempowerment, poverty, stress and marginalization of First Nations communities and their health.

Structural Intervention Strategies for Diabetes Related Complications

Health outcomes depend on managing the disease effectively, and without access to the necessary tools and strategies, Canadians living with diabetes will not be able to achieve optimal results. (CDACPGEC, 2008, p. S3)

Systematic underfunding of First Nations health and social services, necessary to address the consequences of colonization (Waldram, Herring and Young 2006) and pervasive poverty are major contributors to the inequities of diabetes related complications in First Nations communities. As discussed in The Report on the Royal Commission on Aboriginal Peoples (RCAP, 1996), tackling these roots causes is necessary to improve many social determinants, including education, housing, economic development, water and health services. Yet in 2006, the Kelowna Accord, a five year plan developed by the Canadian government and Aboriginal leaders to address these social determinants was not funded. It is unclear if the Canadian government will implement this plan in the future. If implemented, it may take decades to significantly reduce diabetes related complications.

Farmer and colleagues (2006, p.1690) argue that health care workers can help to address health inequities by “resocializing” illness, and practitioners “must make common cause with others who are trained to intervene more proximally”, even when there is little political will to improve social determinants. While they are not a substitute for strategic, long-term, proximal improvements in the quality of social determinants of health, structural interventions informed by an understanding of structural violence can ameliorate some health inequalities immediately. We recommend that health care providers advocate for structural interventions to reduce the development of diabetes related complications among Aboriginal people as follows:

Education

1. Promote the knowledge of the barriers to diabetes self-management and education Aboriginal people might experience among care providers and community members.
2. Promote the sharing of success stories of Aboriginal people living with diabetes in order to counteract fatalism.
3. Educate health care providers about traditional Aboriginal approaches to health so they can confidently support patients’ personal choices.
4. Educate health care providers about Aboriginal concepts of wellness such as the Medicine wheel and the Aboriginal concept of health as a balance of physical, mental, emotional and spiritual wellbeing.
5. Increase awareness of community-specific barriers to healthy eating and physical activity, and support community action.

Services

6. Develop culturally safe diabetes care using a community-based approach, including self-management education and mental health support services, with optional services incorporating aspects of traditional Aboriginal holistic wellness.
7. Provide access and referrals to appropriate holistic mental/emotional/spiritual health services for Aboriginal people with diabetes.
8. Develop safe, community-appropriate physical fitness activities and formally prescribe these to patients during clinic visits.
9. Move beyond a physical focus of diabetes health and connect patient with culturally safe addictions, mental health and smoking cessation services as necessary.
10. Encourage interdisciplinary diabetic health care so that traditional Aboriginal practitioners, mental health workers and primary care practitioners work synergistically to support patients with diabetes.

Table 1

Focus Group Details

Category	Participant details	Number of Participants
Health Care Providers	Community health and nutrition	4
	Diabetes Network workers, includes on and off reserve	5
	Physicians	4
	Long-term Care Staff	8
	Mental Health workers	7
Elders	From participating communities	10
Recreation staff	Communities combined	4
Community Members with diabetes	Community 1	6
	Community 2	2
	Community 3	6
	Community 4	6
	Community 5	8
	Community 6	6
Total	13 focus groups	76 participants

Table 2

Clinical guidelines for healthy self-management behaviours

Healthy self-management behaviours
Diet
Self-Monitoring of Blood Glucose
Medications
Physical activity
Smoking cessation

References

- Aluli, N. E., Jones, K. L., Reyes, P. W., Brady, S. K., Tsark, J. U., & Howard, B. V. (2009). Diabetes and cardiovascular risk factors in Native Hawaiians. *Hawaii Medical Journal*, 68(7), 152-157.
- Abraham, C. (2011). How the diabetes-linked "thrifty gene" triumphed with prejudice over proof. *The Globe and Mail*. Retrieved from www.theglobeandmail.com.
- Brave Heart, M., & De Bruyn, L. M. (1998). The American Indian Holocaust: Healing historical unresolved grief. *American Indian and Alaska Native Mental Health Research*, 8 (2), 56-78.
- Canadian Diabetes Association Clinical Practice Guidelines Expert Committee [CDACPGEC] (2008). Canadian Diabetes Association 2008 clinical practice guidelines for the prevention and management of diabetes in Canada. *Canadian Journal of Diabetes*, 32(Suppl 1), S1-201.
- Carrasco, E. P., Perez, F. B., Angel, B. B., Albala, C. B., Santos, J. L., Larenas, G. Y., Montalvo, D. V. (2004). Prevalence of type 2 diabetes and obesity in two Chilean Aboriginal populations living in urban zones. *Revista Médica de Chile*, 132(10), 1189-1197.
- Commission on Social Determinants of Health. (2008). *Closing the gap in a generation: health equity through action on the social determinants of health*. Geneva: World Health Organization.
- Daniel, M., Rowley, K. G., McDermott, R., Mylvaganam, A., & O'Dea, K. (1999). Diabetes incidence in an Australian Aboriginal population. An 8-year follow-up study. *Diabetes Care*, 22(12), 1993-1998.
- Dannenbaum, D., Kuzmina, E., Lejeune, P., Torrie, J., & Gangbe, M. (2008). Prevalence of diabetes and diabetes-related complications in First Nations communities in northern Quebec (Eeyou Istchee), Canada. *Canadian Journal of Diabetes*, 32(1), 46-52.
- Davis, T. M., McAullay, D., Davis, W. A., & Bruce, D. G. (2007). Characteristics and outcome of type 2 diabetes in urban Aboriginal people: The Fremantle diabetes Study. *Internal Medicine Journal*, 37(1), 59-63.
- Dinca-Panaitescu, S., Dinca-Panaitescu, M., Bryant, T., Daiski, I., Pilkington, B., & Raphael, D. (2010). Diabetes prevalence and income: Results of the Canadian Community Health Survey. *Health Policy*.
- Dyck, R. F., & Tan, L. (1994). Rates and outcomes of diabetic end-stage renal disease among registered native people in Saskatchewan. *Canadian Medical Association Journal*, 150(2), 203-208.
- Farmer, P. (2004). An anthropology of structural violence. *Current Anthropology Journal*, 45, 305-326.
- Farmer, P. (2005). *Pathologies of power: Health, human rights, and the new war on the poor*. Berkeley: University of California Press.
- Farmer, P., Nizeye, B., Stulac, S., & Keshavjee S. (2006). Structural violence and clinical medicine. *PLoS Medicine* 3(10), e449.
- Fee, M. (2006). Racializing narratives: obesity, diabetes and the "Aboriginal" thrifty genotype. *Social Science & Medicine*, 62(12), 2988-2997.
- Gaede, P., Lund-Andersen, H., Parving, H. H., & Pedersen, O. (2008). Effect of a multifactorial intervention on mortality in type 2 diabetes. *The New England Journal of Medicine*, 358(6), 580-591.
- Hanley, A. J., Harris, S. B., Mamakeesick, M., Goodwin, K., Fiddler, E., Hegele, R. A., . . . Zinman, B. (2005). Complications of type 2 diabetes among Aboriginal Canadians: Prevalence and associated risk factors. *Diabetes Care*, 28(8), 2054-2057.

- Harjo, T. C., Perez, A., Lopez, V., & Wong, N. D. (2011). Prevalence of diabetes and cardiovascular risk factors among California Native American adults compared to other ethnicities: The 2005 California Health Interview Survey. *Metabolic Syndrome and Related Disorders*, 9(1), 49-54.
- Health Canada. (2006). *The human face of mental health and mental illness in Canada*. Retrieved from http://www.phac-aspc.gc.ca/publicat/human-humain06/pdf/human_face_e.pdf
- Holman, R. R., Paul, S. K., Bethel, M. A., Matthews, D. R., & Neil, H. A. (2008). 10-year follow-up of intensive glucose control in type 2 diabetes. *The New England Journal of Medicine*, 359(15), 1577-1589.
- Iwasaki, Y., Bartlett, J., & O'Neil, J. (2004). An examination of stress among Aboriginal women and men with diabetes in Manitoba, Canada. *Ethnicity & Health*, 9(2), 189-212.
- Kirmayer, L. J., Brass, G. M., Holton, T., Paul, K., Simpson, C., & Tait, C. (2007). *Suicide among Aboriginal People in Canada*. Ottawa: Aboriginal Healing Foundation.
- Kirmayer, L. J., Brass, G. M., & Tait, C. L. (2000). The mental health of Aboriginal peoples: Transformations of identity and community. *Canadian Journal of Psychiatry*, 45(7), 607-616.
- Kirmayer, L. J., & Guthrie Valaskakis, G. (Eds.). (2009). *Healing traditions: The mental health of Aboriginal peoples in Canada*. Vancouver: UBC Press.
- Ley, S. H., Harris, S. B., Mamakeesick, M., Noon, T., Fiddler, E., Gittelsohn, J., . . . Hanley, A. J. G. (2009). Metabolic syndrome and its components as predictors of incident type 2 diabetes mellitus in an Aboriginal community. *Canadian Medical Association Journal*, 180(6), 617-624.
- Ley, S. H., Hegele, R. A., Harris, S. B., Mamakeesick, M., Cao, H., Connelly, P. W., . . . Hanley, A. J. (2011). HNF1A G319S variant, active cigarette smoking and incident type 2 diabetes in Aboriginal Canadians: A population-based epidemiological study. *BMC Medical Genetics*, 12(1), 1.
- Maar, M., Erskine, B., McGregor, L., Larose, T. L., Sutherland, M. E., Graham, D., . . . Gordon, T. (2009). Innovations on a shoestring: A study of a collaborative community-based Aboriginal mental health service model in rural Canada. *International Journal Mental Health Systems*, 3(27).
- Maar, M., Gzik, D., & Larose, T. (2010). Beyond expectations: Why do Aboriginal and Euro-Canadian patients with type 2 diabetes on a northern, rural island demonstrate better outcomes for glycemic, blood pressure and lipid management than comparison populations? *Canadian Journal of Diabetes*, 34(2), 127-135.
- Maar, M., & Shawande, M. (2010). Traditional Anishinabe healing in a clinical setting: The development of an Aboriginal interdisciplinary approach to community-based Aboriginal mental health care. *Journal Of Aboriginal Health*, 6(1), 18-27. Retrieved from http://www.naho.ca/jah/english/jah06_01/v16_l11_Traditional_Anishinabe_Healing.pdf
- Manitowabi, D., & Maar, M. (2011). Coping with colonization: Aboriginal diabetes on Manitoulin Island. In J. Fear-Segal & R. Tillett (Eds.), *Indigenous bodies: Reviewing, relocating, reclaiming*. Albany: SUNY
- Musselman, D. L., Betan, E., Larsen, H., & Phillips, L. S. (2003). Relationship of depression to diabetes types 1 and 2: epidemiology, biology, and treatment. *Biological Psychiatry*, 54(3), 317-329.
- Nsiah-Kumi, P. A., Beals, J., Lasley, S., Whiting, M., Brushbreaker, C., Erickson, J., . . . Larsen, J. L. (2010). Body mass index percentile more sensitive than acanthosis nigricans for screening Native American children for diabetes risk. *Journal of the National Medical Association*, 102(10), 944-949.
- Oster, R. T., & Toth, E. L. (2009). Differences in the prevalence of diabetes risk-factors among First Nation, Metis and non-Aboriginal adults attending screening clinics in rural Alberta, Canada. *Rural Remote Health*, 9(2), 1170.

- Patel, A., MacMahon, S., Chalmers, J., Neal, B., Woodward, M., Billot, L., . . . Williams, B. (2007). Effects of a fixed combination of perindopril and indapamide on macrovascular and microvascular outcomes in patients with type 2 diabetes mellitus (the ADVANCE trial): A randomised controlled trial. *Lancet*, 370(9590), 829-840.
- Poudrier, J. (2007). The geneticization of Aboriginal diabetes and obesity: adding another scene to the story of the thrifty gene *Canadian Review of Sociology and Anthropology*, 44(2), 237-261.
- Reading, J. (2009). *The crisis of chronic disease among Aboriginal Peoples: A challenge for public health, population health and social policy*. Victoria: University of Victoria.
- Richmond, C. A., & Ross, N. A. (2009). The determinants of First Nation and Inuit health: A critical population health approach. *Health Place*, 15(2), 403-411.
- Roberts, H., Jiles, R., Mokdad, A., Beckles, G., & Rios-Burrows, N. (2009). Trend analysis of diagnosed diabetes prevalence among American Indian/Alaska native young adults--United States, 1994-2007. *Ethnicity and Disease Journal*, 19(3), 276-279.
- Royal Commission on Aboriginal Peoples[RCAP]. (1996). *Volume 3: Gathering strength*. Ottawa: Royal Commission on Aboriginal Peoples.
- Stratton, I. M., Adler, A. I., Neil, H. A., Matthews, D. R., Manley, S. E., Cull, C. A., . . . Holman, R. R. (2000). Association of glycaemia with macrovascular and microvascular complications of type 2 diabetes (UKPDS 35): Prospective observational study. *British Medical Journal*, 321(7258), 405-412.
- UK Prospective Diabetes Study (UKPDS) Group. (1998). Tight blood pressure control and risk of macrovascular and microvascular complications in type 2 diabetes: UKPDS 38. UK Prospective Diabetes Study Group. *British Medical Journal*, 317(7160), 703-713.
- Waldram, J. B., Herring, D. A., & Young, T. K. (2006). *Aboriginal health in Canada: Historical, cultural and epidemiological perspectives* (2nd ed.). Toronto: University of Toronto Press.
- Wang, Z., Hoy, W. E., & Si, D. (2010). Incidence of type 2 diabetes in Aboriginal Australians: An 11-year prospective cohort study. *BMC Public Health*, 10, 487.
- Wesley-Esquimaux, C. C., & Smolewski, M. (2004). *Historic trauma and Aboriginal healing*. Ottawa: Aboriginal Healing Foundation.
- Wiemann, C. (2006). Improving the mental health status of Canada's Aboriginal youth. *Journal of the Canadian Academy Child and Adolescent Psychiatry*, 15(4), 157-158.
- Young, T. K., Reading, J., Elias, B., & O'Neill, J. D. (2000). Type 2 diabetes mellitus in Canada's First Nations: Status of an epidemic in progress. *Canadian Medical Association Journal* 163(5), 561.
- Yu, C. H., & Zinman, B. (2007). Type 2 diabetes and impaired glucose tolerance in aboriginal populations: A global perspective. *Diabetes Research Clinical Practice*, 78(2), 159-170.