Exploring the Experience of Type 2 Diabetes in Urban Aboriginal People

David Gregory, Wendy Whalley, Judith Olson, Marilyn Bain, G. Grace Harper, Leslie Roberts, and Cynthia Russell

L’expérience du diabète chez les autochtones (inscrits et non inscrits) vivant en milieu urbain a été explorée dans le cadre d’une étude qualitative. Puisque les chercheurs se sont penchés presque exclusivement sur les autochtones vivant dans des réserves et des communautés rurales isolées du Canada, des entrevues ont été menées auprès de participants (n = 20) résidant dans la ville de Winnipeg, au Manitoba. Des données obtenues, trois thèmes ont été retenus: le diabète en tant que maladie omniprésente et incontrôlable; au-delà d’un taux élevé de sucre — la manifestation du diabète à travers les changements dans le corps; et le bon, le mauvais et le non efficace — les interactions avec les pourvoyeurs de soins. Les résultats de cette recherche et de recherches antérieures appuient l’existence d’un modèle de diabète pan-autochtone. Cet état de fait contemporain et culturel semble transcender la géographie et comporte des implications quant aux approches de prévention et de traitement utilisées dans les programmes et les services de santé des autochtones atteints de diabète.

The experience of diabetes among urban Aboriginal people (status and non-status Indians) was explored through a qualitative study. Because researchers have focused almost exclusively on Aboriginal people living on reserves or in isolated rural communities in Canada, this study conducted face-to-face interviews with participants (n = 20) living in the city of Winnipeg, Manitoba. The data generated 3 themes: diabetes as an omnipresent and uncontrollable disease; beyond high sugar: diabetes revealed in bodily damage; and the good, the bad, and the unhelpful: interactions with health-care providers. Findings from this study and previous research support the existence of a pan-

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Aboriginal model of diabetes. This contemporary cultural stance appears to transcend geography and has implications for the prevention and treatment approaches used in programs and health services for Aboriginal people living with diabetes.

One of the major health problems among the Aboriginal people of Canada (status and non-status Indians, Métis, and Inuit) is non-insulin-dependent diabetes mellitus, or type 2 diabetes (Hanley et al., 1995). Compared to the general Canadian population, disproportionate numbers of Aboriginal people are diagnosed with diabetes as well as its preventable late complications (Anderson & Dean, 1990).

An interplay of genetics and sociocultural determinants is thought to contribute to the prevalence of diabetes among Aboriginal people (Daniel & Gamble, 1995; Eaton, 1977; Jackson & Broussard, 1987; Neel, 1962; Young, Szathmáry, Evers, & Wheatley, 1990). Aboriginal people have experienced significant social and cultural changes since the arrival of the Europeans. Their spiritual beliefs, culture, food sources, and environments changed radically in a relatively short period of time. Now, many Aboriginal communities are characterized by poverty, unemployment, and other socio-economic conditions conducive to health and well-being (Gregory, Russell, Hurd, Tyance, & Sloan, 1992) and Aboriginal people are susceptible to chronic diseases such as obesity, cardiovascular disease, hypertension, and diabetes.

Researchers have focused on the experience of diabetes among Aboriginal people living on reserves or in isolated communities (Garro, 1994a, 1994b; Hanley et al., 1995; Lang, 1985; Parker, 1994). Exploration of the health concerns of urban Aboriginal people in Canada is a recent phenomenon (Marshall, Johnson, & Martin, 1992; Shestowsky, 1995) and only a few researchers have reported the experiences of these people living with diabetes (Hagey, 1984; Travers, 1995). This knowledge deficit is remarkable given that almost three quarters of all Aboriginal people in Canada live “off reserve” (Shestowsky).

The purpose of this study was to determine the experience of Aboriginal people living with type 2 diabetes in the city of Winnipeg, Manitoba. Interviews with participants were organized around the central research question What is the general experience of Aboriginal people living with diabetes in an urban setting?

Research Design, Method, and Data Analysis

Given the paucity of knowledge about the experience of diabetes among urban Aboriginal people, a naturalistic approach (Lincoln &
Guba, 1985) was appropriate to explore this phenomenon. Specifically, the method applied was person-centred interviewing (Levy & Hollan, 1998).

After approval had been received from an ethical review committee, data were collected over a period of 10 months. Participants \( n = 20 \) recruited from urban diabetes resource clinics were interviewed in English by a research assistant who was an Aboriginal. The lead author held a series of workshops with the research assistant on the fundamentals of interviewing and generation of qualitative data, such as the practicalities and conceptual issues associated with interviewing, tape recording, and the use of self as instrument.

Participants declared themselves to be urban Aboriginals. Although all Aboriginal people (Indian, Métis, Inuit) were eligible, the participants were exclusively status and non-status Indians, primarily Cree. Face-to-face interviewing was guided by a semi-structured interview schedule based on the literature as well as the researchers' experiences with chronic illness and with this population. The duration of the interviews ranged from 30 to 90 minutes, averaging 1 hour. The questions included: What is hard or difficult about living with diabetes? and What is your understanding of diabetes? The interviews took place in participants' homes and were audiotaped. The audiotapes were transcribed verbatim using WordPerfect software. The research team conducted ongoing evaluation of the data set for saturation and observed repetition of patterns (i.e., saturation) upon completion of the 20th interview.

The transcripts underwent standard content analysis as recommended by Burnard (1991). Team members reviewed the transcripts as they were generated to ensure quality and completeness of the database. Patterns and unique textual data (events, experiences, or reported behaviours) were coded, aggregated into categories, and abstracted into themes. Each interview was coded separately by three of the investigators, who then met as a group to discuss the clustering of the data into categories and themes. The process entailed establishing consensus and truth value within the research team as to the interpretation of the data (Munhall, 1994). Although member checks were not conducted, trustworthiness was enhanced by the presence of the research assistant, who participated in the ongoing data analysis, offering feedback based on her professional and personal experiences with diabetes as a health-care provider and as a member of the Aboriginal community.
Results

The majority of the 20 participants were women (60%, n = 12) averaging 53 years of age (range = 28–68); most of the women (n = 5) were in their sixth decade of life. The men averaged 50 years of age (range = 43–60). The participants had lived in Winnipeg from 0.8 to 62 years, for a mean of 23 years. One participant had lived in Winnipeg less than 1 year; the others had lived in Winnipeg a minimum of 7 years. Participants had relocated from northern and other rural reserves throughout Manitoba. Additional demographic data are presented in Table 1.

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Three theme clusters (see Figure 1) generated from the data provide a preliminary understanding of the experience of urban Aboriginal people living with diabetes. Data excerpts are representative of the 20 participants.

| Figure 1 | The Experience of Type 2 Diabetes among Urban Aboriginal People |
|----------|-----------------------------------------------------------------
| 1.       | Diabetes as an Omnipresent and Uncontrollable Disease |
| 2.       | Beyond High Sugar: Diabetes Revealed in Bodily Damage |
| 3.       | The Good, the Bad, and the Unhelpful: Interaction with Health-Care Providers |
Diabetes as an Omnipresent and Uncontrollable Disease

Diabetes was “all around” the participants. Every person (n = 20) identified immediate family members diagnosed with and treated for diabetes. Extended family members — grandparents, aunts, uncles, nephews, and cousins — were also living with diabetes.

My grandfather from my mother’s side — he was a diabetic. My husband’s mother was a diabetic. My sister and my brother. My dad also had diabetes, but he died. My other sister is a borderline diabetic.

Diabetes has been around my life since I was born. My grandparents had it. My niece has it. My husband has it. I have it. My sisters are borderline. So diabetes is all around me.

Each participant, prior to being diagnosed, felt at risk for diabetes. Collectively they indicated that their young children were the only family members not afflicted with the disease, and they acknowledged the fact that the children could develop it over time.

Participants were fearful of diabetes because they had witnessed the plight of family members and friends subjected to its ravages. The signature of diabetes on their bodies included amputated feet, legs, and hands. Many participants knew Aboriginal people whose kidneys had failed because of diabetes, requiring them to undergo renal dialysis.

I fear sometimes...what happens if it [blood sugar] really goes up and they [the physicians] can’t control it? Especially when the doctor told me that any little cut I have I should take care of it — that’s scary. Like, I’ve seen friends lose their legs...cut their legs off because of diabetes and they end up with an artificial leg.

The people I see...how they are when they have diabetes. Some of them are really bad. Like, our friend, he died, not even a year ago, eh. They cut off both legs. They cut off his fingers. He was really in bad shape. He only lasted two years. Diabetes scares me. It scares me because I could lose my feet, eh. Lose my hands and lose my sight.

Participants who had witnessed the suffering of others expressed the view that diabetes would progress and run its “natural” course, despite the efforts of health-care providers and the persons themselves. They spoke of the inevitability of amputations, vision loss, renal failure, and eventual death. Most participants normalized the catastrophic events associated with advanced neuropathy, seeing them as part of the natural history of diabetes. They saw themselves as caught up in a disease that, on a personal and collective level, defied control.

Well, they [people with diabetes] have to go on a diet. They have to take needles. They have to go on dialysis. They have to lose their toes, their feet — the people I know anyway, and they’re my family I’m talking about.
My attitude is because there is no cure for it, sure we can control it, but
the way I look at it, what's the use? Why go to a doctor, why follow a
diet...sooner or later you are going to die from this disease anyway. You
are going to lose a leg, you are going to lose a hand, you're going to go
blind. That's my attitude, eh.

There is nothing you can do about it. You wish to hell it had never come
around — stayed where it was before it found you, eh. There's nothing
you can do about it. There's no cure for it.

Participants interacted with and cared for family members and
friends whose diabetes had progressed to the extent that serious com-
plications were grossly evident. In struggling with the disease, each
participant was confronted with a traumatic family legacy, fears caused
by witnessing the suffering of others, and acceptance that diabetes
would lead to death. In the face of overwhelming subjective experience
confirming that diabetes was essentially an uncontrollable disease, they
felt they were being held personally accountable by health-care
providers for its control. This placed many of them in a classic “double
bind”: encouraged to assume personal responsibility for a disease that,
based on their experiences, did not respond well to professional treat-
ment. Many of the participants blamed themselves for their symptoms
and complications, vowing to “try harder” to control their diabetes.
They experienced tension in reconciling self-blame with a disease that
resisted control.

The doctor said there is no way to control it. It’s only me that has to do it.

My leg was sore and that's when the doctor said that it is only me that
can control it. There is nobody else. There's no cure for diabetes — it's
you. If you follow your diet and your exercise and go for walks and stay
away from fried foods.

That's what's wrong with me. It's my fault. I didn't make too much
changes. This is why my sugar diabetes is so bad. That's my fault. I'm
going to try very hard in the new year. I'm going to try very hard. I'm
going to try very hard, so help me God. I will, you know, try harder.

Participants said they followed a “special” diet for their diabetes.
Those who had been diagnosed many years earlier indicated that they
were still “on a diabetic diet.” Before being diagnosed, participants had
usually fried their food. Frying was an established method of food
preparation from early in their lives, a deeply ingrained life-pattern.

When I was growing up, we used to have fried fish or fried baloney. I
don't like boiled stuff, but I got no choice.

I was always used to eating a lot of sweets and deep-fried foods. I'm still
working on the diet. It's hard to change a life. I've been doing it [eating
fried foods and sweets for 50 years and now I have to change in three or four months?

They identified suddenly being instructed to stop eating fried foods and sweets as one of the most difficult aspects of living with diabetes.

Two of the participants reported that they modified their cooking habits to benefit their children and other family members. Concerned that their children might develop diabetes, they tried to promote better eating habits within the family.

I'm worried about my kids. I want them to change their eating patterns so they can eat the same kind of foods I'm eating — so we can help each other instead of eating all this food we should not be eating — pastry stuff. Now all of us, we changed our eating pattern at home and it helps. They help me along with it too — they eat what I eat and we don't bring in anything that we shouldn't.

In contrast, the remaining participants prepared “diabetic diet foods” for themselves or their partner while their children continued to have other meals with fried foods and sweets.

My wife has to cook different for me than she does for the rest of the family. Like they can have mashed potatoes. I can't.

This practice reinforced the idea that family members living with diabetes were placed on a “special diet” that concerned only them. Other family members ate meals that had been the standard cuisine prior to the diabetes diagnosis.

Beyond High Sugar: Diabetes Revealed in Bodily Damage

When participants were asked, “What causes diabetes?” more than half (55%, n = 11) replied, “I don’t know.” Despite prompting by the interviewer, they were unable to identify the cause. The remaining participants attributed diabetes to various sources: consuming excessive amounts of alcohol, genetics, eating too many sweets, obesity, dietary change from traditional to processed foods, and the arrival of the “White man’s” disease (diabetes).

When asked whether they knew what diabetes was, six participants said “yes” and proceeded to describe the disease, speaking of “high blood sugar” and the need to keep their blood sugars under control; they mostly accounted for their diabetes through the lens of the biomedical model. The remaining participants (n = 14) were unable to provide an overview or description of diabetes in their own words.
Notably, the majority of participants who had been diagnosed many years earlier were unable to articulate the cause of their disease.

No. I don't know anything about it. All I know is I have diabetes. [diagnosed 20 years previously]

All I know is that it is diabetes and that's it. I don't know too much about it. It just gets you sick. [diagnosed 25 years previously]

However, these participants were able to articulate the consequences of diabetes and the trauma it caused.

Most participants came to know about their own diabetes through the progress of physical symptoms. Diabetes was revealed in bodily destruction, and "knowing about diabetes" was rooted in their corporeal experiences. It was at the point of serious bodily damage that many participants began to recognize their peril, coming to realize the destructive power of diabetes and its impact in the context of their own bodies. Frequently, participants did not follow their diets or exercise regimens until they noticed significant bodily changes. Diabetes did not appear to become real for them until their bodies were grossly affected.

When I was first diagnosed, I didn't do anything. I kept on for a few years the way I was living. Kept drinking until it started getting too bad and I had to start taking treatments. [diagnosed 10 years previously]

The Good, the Bad, and the Unhelpful: Interactions With Health-Care Providers

Two participants had experienced positive interactions with health-care providers, commenting on the supportive manner in which they had been treated. These health-care providers did not issue ultimatums or make rules. Rather, they gave advice and information and permitted the person with diabetes to accept or reject what was being offered. A dietitian who the took time to "explain everything" and encouraged the participant to help herself was perceived as supportive.

I was 249 pounds. But the dietitian didn't tell me to lose weight, but she told me the fact that being overweight has a lot to do with what happened to me — and probably what kind of foods I ate. She told me I’d feel a lot better if I lose weight, but she didn’t say, "Lose weight!" That’s up to you — she said — whatever I want to do. So I thought, I’ll do it.

Living with diabetes meant trying to follow a set of rules and regulations prescribed by health-care practitioners. Participants were told "what to do" and "what not to do." Interactions with health-care practitioners usually resulted in reinforcement of rules concerning diet,
blood sugar levels, medications, and exercise. When they did not follow rules they were sometimes berated and subjected to threats.

They told me that the only way I could prevent these symptoms from happening is by doing what my doctor told me to do — like my diet and physical activities. I forgot to take my pills and the doctor said that was not nice. He said, “You've got to try and take them every day.” And then my blood sugar shot up and then that's when he told me if I didn’t lose weight that I would have to take needles [insulin]. And then I got mad and didn’t bother taking needles.

The doctor I went to see, he said, “If you do what I tell you to do — you will be OK.” The doctor — he’s sort of mad I wasn’t following my diet.

The doctor scared me. He said that I could die, you know, if I don’t listen. He scared me. He really scared me.

Participants reported feeling rushed during visits to their physician and the diabetes clinic. Little time was available for explanation and one-on-one instruction, and participants said that limited teaching and learning occurred during the visits. The focus of physician encounters was most often reported as a review of blood sugars and assessment of medications.

The nurse talks to me about my diet. You see — the doctor I went to — he never took time to talk to me at all. He was always in a rush.

There are a lot of people they have to look after. They only have time to see you for a short time because there are so many people with diabetes. You have to be patient. This is why it’s so hard to try and get the answers you want, because it has to take patience. I know a lot of people — sometimes they feel like nobody wants to listen. If we had a lot more time, you could talk about diabetes.

More than half the participants \( n = 11 \) reported that they had been given pamphlets on diabetes. Two said they found these helpful, but the majority identified problems with information presented in this manner.

I got all the pamphlets and I tried to read them and I can’t. It is hard to understand them, eh. It’s a hard thing. I can’t bring myself to learn about diabetes myself. I have to have some help, somebody to talk with about it.

She gives me little pamphlets. I said, “Thank you,” and I put it somewhere on top of the fridge and that's where they stay, really.

For the majority of the participants, reading was not the preferred method of learning about diabetes. Interacting directly with health-care providers was seen as more effective. Moreover, learning from other Aboriginal people living with diabetes was identified as a helpful and welcome strategy.
I like the people coming and talking to me about diabetes. They have diabetes. I can’t read the pamphlets and I never bothered anyway.

There are a lot of things I wish I could share with somebody. Somebody I could talk to about diabetes — that would help. It would help a lot of people if somebody talked to them.

Two participants voiced the need for Aboriginal educators. One participant suggested that a diabetes clinic administered and managed by Aboriginal people would help address deficiencies in the health-care system.

I would like to see our own native women and young men become nurses...with some experienced teachers guiding us along. Like our own people, like you [Native research assistant] would go out and do the teaching.

I think we should have our own diabetes clinic, and I mean our own. Aboriginal people, eh, our own nurse, our own doctor, you know. Our own diabetes clinic run by Native people. Native doctors, Native nurses — like they should do the teaching to me about diabetes...what it does to my body, eh. How can I take care of myself, eh? What this disease is. The White doctors and nurses, they say, “This is what you have. This is what you take. This is what you do. You’re not supposed to eat this,” and then you go. I would rather have our own and have these people spend time with me and explain diabetes to me — the information I never had when I was first diagnosed.

The use of “Indian medicine” (as the participants called it) and other traditional approaches to healing were explored. Of the 20 people interviewed, four reported using Indian medicine. One of the four people used traditional medicine for “colds” but not for treating his diabetes. Beyond the use of medicines, participants said they looked to Elders for understanding and advice about living with diabetes.

Yes I do. Whatever I get from my Elders — they are teaching me — I use it, plus the medication that the doctors give me.

Participants indicated that accessing traditional medicine in the urban setting was difficult. A few participants suggested that they would use these medicines if they were more readily available.

There is Indian medicine, but when you live in the city it is difficult to get. It helps a lot of people. It is helping them on the reserves.

Discussion

This study has afforded an exploration of type 2 diabetes among urban Aboriginal people (status and non-status Indians). Three main findings
warrant discussion: a cultural model of diabetes, the absence of integrated culturally appropriate services in the urban context, and implications for programming and delivery of services to Aboriginal people.

Pan-Aboriginal Cultural Model of Diabetes

To date, studies have focused almost exclusively on the experience of diabetes among people living on Indian reserves in Canada (Garro, 1994a, 1994b; Hanley et al., 1995). It should be noted that the cultural model as described in these studies held true for the urban participants in the present study. There appears to be a shared set of understandings, or a cultural model, of diabetes, whether rural (Garro, 1994a, 1994b; Parker, 1994) or urban. However, participants in the present study were primarily unemployed and on average had a Grade 8 education. The impact of poverty combined with cultural dimensions must be considered in the context of the model. Keeping this caveat in mind, the pan-Aboriginal model is characterized by the inevitability of developing diabetes, the virulent progression of a disease that defies personal and professional control, and the fear of what diabetes does to one’s body and one’s life (Garro, 1994a, 1994b). Participants constructed this model as a result of their own experiences with diabetes as well as the suffering of family members and others in the Aboriginal community.

The findings of this modest study lend support to a pan-Aboriginal cultural model of diabetes that transcends geography. As Garro (1994b) observes, “this cultural model provides a framework for interpreting perceived symptoms, making causal attributions, comprehending new information, and taking action in response to illness” (p. 184). Thus there are implications for the entire approach to this disease, including primary and secondary prevention (Daniel & Gamble, 1995) and disease management (Hagey, 1984; Hagey & Buller, 1983). The conceptualization of diabetes within the pan-Aboriginal cultural model is vastly different from that within allopathic and non-Aboriginal explanatory models. For example, the cultural model suggests that disease management is beyond the individual’s control — diabetes defies control and is part of a complex set of personal, social, cultural, and historical interactions. Allopathic and non-Aboriginal models, in contrast, focus on individual, personal control and responsibility for the disease (Garro, 1994a; Paterson, Thorne, & Dewis, 1998). Not unexpectedly, therefore, Aboriginal persons, operating from within the latitudes of this cultural model, may be perceived by health-care providers as abdicating responsibility for their disease. In reality, such behaviours by Aboriginal people are in accord with their understanding of diabetes.
The fact that current preventive interventions are not “working” for Aboriginal people may also be partly explained through this cultural model. The findings challenge researchers to disentangle the interaction of poverty on this pan-Aboriginal model of diabetes.

**Diabetes Care in the Urban Context**

The urban setting offers an infrastructure for diabetes care. There are numerous specialists (e.g., endocrinologists, nurse clinicians, diabetes educators, dietitians) as well as organizations (e.g., the Canadian Diabetes Association) committed to addressing diabetes. The participants in this study either did not access this abundance of resources or reported them as unhelpful. Almost all participants described distressing confrontations with health-care providers, commented that information about their diabetes was rule-bound, and indicated that many of the diabetes educational pamphlets were unhelpful. These findings are surprising in light of Hagey’s (1984) classic work with the Anishnawbe Health Toronto community health centre, which demonstrated the importance of culturally relevant approaches to diabetes care. Daniel and Gamble (1995) stress the need for such approaches to diabetes care and identify Canada’s lack of “development, implementation, and evaluation of an integrated primary and secondary diabetes prevention program” (p. 254). There remains the need to move beyond “diabetes rhetoric” in the urban context. The findings of the present study reinforce the necessity of culturally competent and integrated approaches that consider individual and community perspectives in the prevention and treatment of diabetes among Aboriginal people.

**Implications for Programming and Delivery of Services**

The Royal Commission on Aboriginal Peoples (Canada, 1996) recommended that less emphasis be placed on diabetes as a disease entity and that more emphasis be placed on the social, economic, and political factors that influence health. To this end, there is an urgent need for the health-care sector to work in partnership with Aboriginal leaders, agencies, and those living with diabetes. Programming and services must take into account the historical, social, and cultural factors surrounding diabetes. This requires a focus on individuals and their life circumstances in the context of the urban Aboriginal community.

In addition to this macro focus, there is a pressing need for disease specifics to be addressed in a culturally relevant and meaningful manner. The whole approach to diabetes care and education requires
re-examination in light of the emerging pan-Aboriginal cultural model of diabetes and the macro context in which diabetes is experienced (Daniel & Gamble, 1995; Hagey, 1984). Particularly disconcerting to participants in this study were their interactions with health-care providers around issues of diet and food preparation and the focus on rules for managing their diabetes. Although there have been some individual attempts to address these issues (e.g., modest cultural modifications of diabetic teaching aids), there does not appear to be systematic integration of service provision at the micro level for urban Aboriginal people.

A few of the participants identified a need for community-based programming initiated and run by Aboriginal people. They indicated a desire to speak with other Aboriginal people with diabetes and to try traditional approaches to healing. Other researchers (Daniel & Gamble, 1995; Hagey & Buller, 1983; Shestowsky, 1995) have noted the importance of such programming but point out that one of the issues facing urban Aboriginal people is limited access to traditional healing services (Shestowsky). It is clear that meaningful and culturally relevant translation of diabetes-related disease concepts and facilitation of the "uptake" and application of diabetes knowledge requires that Aboriginal people and health-care providers work in partnership.

Aboriginal Health Services (AHS) at the Health Sciences Centre (HSC) invited the research team to present the findings of this study to the health-care community. As a result of the presentation, and in keeping with a commitment to the empowerment of Aboriginal people, the research team is working with AHS and the HSC to bring together communities concerned about diabetes: providers of health and social care; community- and hospital-based agencies (Aboriginal Wellness Centre, Winnipeg Hospital Authority); Diabetes Education Resource; Elders and spiritual leaders; support groups for Aboriginal people living with diabetes; and representatives of urban-based Aboriginal political organizations.

In conclusion, the pan-Aboriginal model of diabetes differs from that of health-care providers and non-Aboriginal society. For Aboriginal people with diabetes, application of understandings generated outside their culture may be at best ineffective and at worst damaging. The pan-Aboriginal model challenges existing approaches to diabetes prevention and treatment. Taking action and moving beyond rhetoric, to design culturally relevant, integrated approaches to the prevention and treatment of diabetes in Aboriginal people, entails partnerships between health-care providers and the Aboriginal community.
Additional research is required to define culturally competent care from the Aboriginal perspective. Successful outcomes related to diabetes care are also predicated upon concomitant efforts at the macro and micro levels.

References


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