

Talking With Their Feet



Non-Attendance of Aboriginal People at Diabetes Clinics

Research funded by



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If You Need More Information or Want to Talk to Us

Thank you for reading this booklet and learning about our study. We encourage you to ask us questions or tell us what you think.

Dr. Paterson can be contacted by e-mail at bapaterson@tru.ca or by phone at 250-852-7288.

A PowerPoint presentation is available about this study and its findings. You can find it at <http://www.tru.ca/nursing.html> and download it at your convenience. You may want to use this presentation to share the findings with others and have a discussion about what the findings mean to you, your community or your organization.

The Interviewers

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sibly deters them from coming back to the clinic.

9. Incorporate traditional teachings to help people understand concepts about the body and diabetes (e.g., use the teaching of the Turtle along with the teaching of Mother Earth, where if you eat well and live well, you can live a long life. Like the turtle, humans must make choices to change or continue with their ways).
10. Consider the physical, mental, emotional and spiritual aspects of the person in providing care, not just the physical parts of diabetes. This can be supported by the use of traditional languages.
11. Offer groups of all-Aboriginal people in diabetes education and for peer support.
12. Use culturally appropriate teaching strategies (e.g., use of elders, talking circles).
13. Provide education about Aboriginal peoples' history, traditions and context (e.g., what Health Canada pays for and what they don't) to all non-Aboriginal diabetes clinic staff.
14. Provide meals, parking costs and transportation if needed.
15. Welcome family and community members, including the children, into the person's clinic appointment.
16. Avoid scare tactics and judgment.
17. Develop ways of appointment scheduling that are more flexible and better suited to needs of people (e.g., longer appointments, more accessible hours, reminder calls).
18. Consider bringing the services that the clinic offers to the people in locations that best suit them (e.g., their homes, their community).
19. Explain to Aboriginal people that service providers are bound by a code of ethics and that means they cannot tell anyone about the person's disease or care. Share what they should do if they believe a service provider has broken that code by telling others about him or her.
20. Develop ways of contacting non-attenders that include learning about why they did not attend and welcoming them back to the clinic if they choose to return.

“TALKING WITH THEIR FEET”

***A RESEARCH STUDY TO FIND THE CAUSES OF AND SOLUTIONS TO
NON-ATTENDANCE OF ABORIGINAL PEOPLE IN DIABETES CLINICS***

About this Booklet

This booklet is a brief overview of a two-year study funded by the Canadian Institutes of Health Research (CIHR) about why some Aboriginal people with diabetes miss appointments or never go to a diabetes clinic even though they are referred to the clinic. This particular booklet is for Aboriginal people with diabetes. It can be used by Aboriginal people with diabetes, as well as people who provide diabetes care and by Aboriginal organizations and communities that provide support and information to Aboriginal people with diabetes.

In the booklet, you will learn about what we found in the study about why some Aboriginal people do not go to diabetes clinics or miss clinic appointments, as well as what could be done to increase their attendance. Throughout the booklet, you will read stories of people that we interviewed. These will not be the actual stories but stories that are a collection of things people told us.

The booklet has been organized this way. First of all, we will tell you about the particular study that led to this booklet, including who the authors are. Next we will review the main causes of non-attendance by Aboriginal people in diabetes clinics that were revealed in the study. We will then conclude the booklet by giving you the solutions to non-attendance identified by the people that we talk to, as well as some information about how to get in touch with us.

About the Study

We are a group of people who are Aboriginal and/or university researchers. In three studies that some of us did before this one, we discovered that many Aboriginal people do not go to diabetes clinics, even when the clinics are in their own communities. We also found that at times the person is blamed for not going to appointments when in fact it is other things that are causing this to happen. In fact, a common perception is that Aboriginal people who do not go to diabetes clinics are irresponsible or just don't care. We called the booklet "Talking with their feet" because we believe Aboriginal people are making a statement that things are not as they should be when they chose not to go to diabetes clinics.

In the study, we hired Aboriginal people, mostly university students, as research assistants in New Brunswick, Newfoundland & Labrador, Nova Scotia, and PEI to talk to people in their province about why some Aboriginal people miss appointments or never go to the diabetes clinic. The research assistants talked to 21 Aboriginal people with diabetes who said they missed appointments or did not go the diabetes clinic ("non-attenders"), 12 people who provided diabetes care to Aboriginal people ("service providers"), and 9 people who are responsible for making decisions about services or programs in diabetes care for Aboriginal people ("policy makers"). About half of the non-attenders lived away from their settlement or reserve. They were aged 18 to 73 years. 11 non-attenders lived in rural or remote communities; the others lived in a city or within 30 kms of a city.

One of the reasons that non-attendance is so critical is that people who do not attend diabetes clinics may not be receiving the information and support they need to make decisions about their diabetes care, to prevent complications of the disease and to live as well as possible. However, the study showed that the impact of non-attendance goes beyond the individual with diabetes. For example, non-attendance may result in the person's family feeling stressed and anxious about the person's health and future. Service providers who are aware of the non-attendance may look at the person as lazy or irresponsible and not offer them the information or support the person needs. Clinics, particularly those located within Aboriginal communities, may lose physicians and other service providers when there are insufficient numbers of patients receiving care to justify the worker's salary.

Solutions to Non-Attendance

Many possible solutions were identified in the study. They are mainly solutions that could be enacted by diabetes clinic staff. Some, however, could be implemented by Aboriginal organizations or communities. Although this list is not everything that could be done to prevent non-attendance, it may give you some ideas that you could put into practice. We have made every effort to use the same words the people used when they talked to us about possible solutions.

1. If you are a service provider meeting with an Aboriginal person for the first time, spend time talking with the person that has diabetes in order to learn his/her health priorities, to understand his/her stories, and build trust in order to ensure attendance at appointments.
2. Provide Aboriginal service providers in the diabetes clinic.
3. Integrate diabetes with other health care services so that the person is able to attend to all his/her health concerns in one place and at one time.
4. Develop systems to communicate about the person's plan of care with Health and Wellness staff in Aboriginal communities.
5. Building relationships between the Aboriginal person and diabetes clinic staff could be supported by having talking circles that enable people to get to know one another.
6. Use a strength-based approach, focusing on the things that already work and trying to improve those that do not. Acknowledge and celebrate every effort of the client to make positive changes, no matter how small. One way of focusing on strengths would be reporting the success stories of people dealing with their diabetes or overcoming their symptoms, which could serve as an example for others.
7. Use individuals in the community who already have the trust of the person with diabetes to teach him/her diabetes management.
8. Find out what the person knows about diabetes and what he or she wishes to know. Many Aboriginal people already know the information about diabetes that is available in the clinics, so repeating the information over and over again does not help, and pos-

The Causes

Some non-attenders who lived in reserve or settlement communities said that the reason they did not go to the diabetes clinic on the reserve/settlement was that they did not trust that the information they gave would be kept secret. Those with multiple health problems were frustrated when specialists “only saw me as parts, not as a whole.” Others spoke of the service providers giving different advice from each other, causing the person “not to know what to do.”

A few people left the clinic when they found that there was a lack of communication between the health services in their community or the hospital and the diabetes clinic staff, resulting in gaps or unnecessary repetitions in their care. In addition, some survivors of residential school experience found having to wait in waiting rooms for care to be reminiscent of waiting for punishment by the teacher or principal in their residential school experience and consequently, avoided going to diabetes clinics.

The study showed that there are many reasons for Aboriginal people to decide not to go to a diabetes clinic or to miss an appointment at the clinic. Most of those reasons are beyond what the person with diabetes does or is; they are because of things such as no transportation or what happens in the clinic. We have described the causes of non-attendance as five categories: (1) lack of a personal and/or cultural fit; (2) relationship issues; (3) practical concerns; (4) personal perceptions of diabetes; and (5) issues regarding diabetes care.

Lack of a Personal and/or Cultural Fit

Story: *Frieda Harper describes herself as a “shy” person who finds it difficult to speak in groups. Frieda’s first time in the clinic involved sitting in a group of non-Aboriginal people to learn about carb counting. Frieda found that the other people in the group had little in common with her. They were mostly retired farmers or business people. What they thought were issues in relation to their diabetes were not Frieda’s issues. For example, one man talked about the trouble he had to stick to his diet when he went on cruises. Frieda has never been farther than the city 30 km away from her community. Frieda also found it hard that the foods the teacher talked about, like shrimp and kiwi, were not foods she was used to eating. Much of what the group was learning were things Frieda already knew because her daughter has had diabetes for 20 years. She was bored and a little upset that she wasn’t learning anything new. She was embarrassed when the teacher asked her a question and she could not get the words out. She never returned to the clinic.*



The most common statement about personal fit was that because the service providers knew so little about the person or his/her situation, they often made assumptions or gave teachings that the person could not follow. For example, some said that diabetes care workers often told them to eat food that was too expensive for them to buy or that was not available in their remote area. They said that this made them not want to go back to the clinic. One woman in a remote village said she was chastised by the clinic staff for not eat

ing enough fresh vegetables when the only fresh vegetables available to her in the winter were bruised and overripe carrots in the local store that cost a great deal to buy. Several referred to the clinic staff's assumption that all their medications would be free as evidence that "they don't know us or know our lives" and they were reluctant to engage with the clinic because of this.

Many people referred to diabetes care as not meeting their individual needs. Several referred to the structure of diabetes education as a rigid and a "one size fits all" model.

Many people talked about the need to tailor diabetes care to the individual. For example, some people expressed a preference for seeing the diabetes service provider in their home rather than a clinic. Others talked about the need to have cultural traditions (e.g., talking circle) included in the education that happened in a diabetes clinic. Still others spoke



of the need to include traditional foods and medicines, as well as traditional healing practices, including the involvement of elders, in diabetes clinics.

Although everyone we talked to agreed that there must be a fit of what happens in the clinic with the person's style of learning, needs, and preferences, there was no consensus about how much culture was important to consider in this regard. For example, some people emphasized that there should be a native language speaker and tangible evidence of a commitment to the health of Aboriginal people, such as Aboriginal people's art or Aboriginal service providers, to make Aboriginal people feel welcome and comfortable. Others, however, believed that if the service providers were approachable, respectful and knowledgeable of Aboriginal culture, that this was sufficient to ensure a cultural fit.

Issues Regarding Diabetes Care

Story: Patricia Bull was referred to the diabetes clinic in her community by her doctor. She never went to the clinic because she was sure that the first thing the clinic staff would do would be to weigh her and then "make a big deal of what the number was." She said, "I already know how huge I am. I don't need them to bring that to my attention. They are going to preach at me and use scare tactics like saying I will be blind if I don't do what they tell me. And they are going to insist that I eat only healthy stuff, like lettuce and broccoli. I know that because my sister went to the diabetes clinic and that's what she told me they did to her. She couldn't eat any of our traditional foods, like seal meat. I know I couldn't live on lettuce and broccoli."

There were many fears expressed about going to a diabetes clinic for the first time, especially about having to face a change in lifestyle for which the person was not ready. Some people expressed a fear that they would be "the only Aboriginal" in group education sessions. Others spoke of a fear that their children would not be welcome in the clinic. Still others stated that they were afraid that they might be required to give personal information that might later be used by insurance companies or unemployment insurance in ways that would affect the person negatively. A few people indicated that they were reluctant to go to the clinic or to be seen in the community with clinic staff because the people in the community "would see me as sick."

There were other issues leading to non-attendance that were identified by people who had experienced care in the clinic, particularly when their expectations for quick, consistent and competent care were disappointed. A few people said that the appointments in the clinic were too long, causing them to be away from their employment and/or children for too much time. Some said they felt rushed by service providers in the clinic. Others said they were frustrated about how long they had to wait between appointments and that the procedures for making appointments were difficult. Still others said they did not learn anything new in the clinic, the service provider delivered a standard message that was not related to the person's life, or that the service provider "only wanted to talk about diabetes", not the other aspects of the person's life that affected the diabetes.

Personal Perceptions of Diabetes

Story: Bill Perley was told he has type 2 diabetes at a regular check-up with his doctor. He had been feeling just fine at the time so was very surprised that he had a disease. Bill has trouble believing he is diabetic even now, two years later. Bill says he knows he should be going to the diabetes clinic but he doesn't think his diabetes is much to worry about. He refers to himself as having "just a touch of diabetes". He points out that almost every second person in his community has type 2 diabetes and because it is so common, type 2 diabetes is "not really a problem." Bill says that type 2 diabetes is much less serious than type 1 diabetes because "if you have type 1, you need to give yourself needles." Bill's wife has kidney disease and is not doing very well. Bill has to look after her, their six children and the housework while working full time at a local garage. He says, "I just don't think my diabetes is something I need to pay attention to right now. There's other more important things in my life."

Several non-attenders we talked to did not see a need to go to the diabetes clinic. Some referred to physicians or nurses telling them that they were "doing fine" or had "borderline diabetes" or "mild diabetes"; they interpreted this as meaning they did not yet have to attend to their diabetes clinic.

Still others talked about "not really believing" they had type 2 diabetes because it could be controlled by diet and they felt "fine." Seeing so many Aboriginal people with diabetes in their own community convinced some non-attenders that there was nothing that the diabetes clinic could do to prevent diabetes problems.

Many people did not view diabetes as a priority in their lives. They said they "forgot" the appointment or did not go to the appointment because they were "stressed out" about other things in their life, mostly family problems. Some service providers described non-attenders as being "overwhelmed" by their lives. They said that there are so many issues in most Aboriginal people's lives, particularly if their families need care, that they don't have the time or the energy to go to the clinic.

Relationship Issues

Story: Erica Augustine went to two appointments at the diabetes clinic before she decided not to return. She was angry about the way she was treated by the clinic staff. She said, "Before they even said hello to me, they were asking me about my blood sugars and telling me I needed to lose weight. They didn't ask about my family or tell me anything about themselves. They were strangers to me, yet they expected me to talk about my life to them. Then on top of everything, I had brought my five kids with me and they made them wait in the waiting room. A nurse told one of my kids to sit down and be quiet. And I asked them if they could tell me what to do about my birth control pill making me gain weight. They said they only dealt with the diabetes. But my life is more than just diabetes."

The quality of the relationship between the person with diabetes and the service providers was highlighted by the majority of people we talked to as a factor that affects people's attendance at diabetes clinics. A common way in which relationship issues were expressed was when the person described behaviour by the service provider that was demeaning, judgmental, blaming, and/or disrespectful, often in the context of the service provider's response when the person had missed an appointment without cancelling. Several people told us that the diabetes clinic had a "three times (of non-attendance) and you're out (no more appointments will be made) policy". They described this policy as discriminatory and unfair because there were often valid reasons why they had not attended the appointment but the service providers rarely asked about these.

Relationship with others was also mentioned as a factor that affected non-attendance. Several non-attenders said that the fact that service providers were "strangers" and that they had no history with them made them shy to confide in them. Many people we talked to said that they preferred to obtain their diabetes advice from people they knew and trusted, such as other people in the community with diabetes or service providers with whom they had a long-standing relationship, such as the local pharmacist.

Most people identified at least one person with whom they had a relationship whose stories about the diabetes clinic affected their willingness to attend the clinic. In most cases, the

storyteller was an Aboriginal friend or family member with diabetes who told “stories” about the diabetes clinic. Many non-attenders said that their decision to avoid the diabetes clinic was in part affected by the stories of their family members or people in the community who had done well even though they did not go to the clinic or who had suffered because a service provider had not treated them well. A common story was that a relative had lived to be old even though he or she had ignored the service provider’s advice. “Horror stories” told by others were also commonplace. These stories emphasized that the service provider was judgmental and did not offer the care the storyteller needed. The influence of these stories was powerful in determining the person’s decision to go to the diabetes clinic.

The service provider’s acknowledgement of the importance of family and community was emphasized by several people as a significant factor in determining their decision to attend or not attend the diabetes clinic. Those who had been told that “there was no room” for their family members to join them in the clinic visit were often reluctant to go back to the clinic. Some people told us that clinic staff had criticized them for their children being noisy and had made racial slurs about Aboriginal people “who don’t know how to parent but have tons of kids.” Such behaviour had resulted in them not returning to the clinic.

Practical Concerns

Story: Thomas Barney was all set to go to his clinic appointment in the nearby city when he realized that his car would not work. He phoned the medical carrier (a person who drives Aboriginal people to their medical appointments) and the carrier said she could pick Thomas up in 15 minutes. However, she told him that before she could drop him off at his appointment, she needed to drop off three other people at other places and for one of those people, she needed to go into to the doctor’s office to translate for the person (a native language speaker). Thomas would have to be late for his appointment because of these things. Thomas tried to phone the clinic to say he would be late. His call went to the clinic answering machine but the instructions about leaving a message were in French. Thomas does not speak French. He hung up and did not go to the appointment. Because he was embarrassed for having missed the appointment, he never went back to the clinic.

Several non-attenders spoke of service providers in the diabetes clinic as being kind, patient and caring. Their reasons for not attending the clinic were because of other things, such as not having transportation to get to the clinic, not having enough money, not being able to get off work, or having no one to care for children. Language barrier was noted by some as a particular concern for older adults who were native language speakers and knew little English or French.



Transportation was a critical issue in regard to non-attendance. Because health care in rural and remote communities may not include diabetes care, some people we talked to had to travel great distances and perhaps stay overnight to attend a diabetes clinic in the closest city. Purchasing meals, staying at a hotel and parking during that time were expenses that many people thought they could not afford. Some people in Newfoundland and Labrador said that this also represented an arduous journey by snowmobile in the winter.

Some non-attenders said that they battled addiction and that this affected their ability to remember appointments. Service providers and policy makers agreed that addiction and stress was a big issue. They also talked about how depression, grief and loss affected people’s willingness to go to the clinic.

The hours of operation of the diabetes clinic were considered by many people to be a barrier to their attending the clinic. Many said that the hours (generally 9-5, Mondays-Fridays) did not fit into their work schedules or would require them to pay for child care. In addition, several people referred to the clinic building as “intimidating” and many referred to the difficulties they had in locating a parking spot as one of the reasons they did not go to the clinic.