

# Living with Diabetes on Baffin Island

## Inuit Storytellers Share Their Experiences

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### ABSTRACT

**Background:** The prevention and management of Type 2 diabetes mellitus has become a concern in Inuit communities across Canada. Although Inuit living with diabetes in remote Canadian Arctic communities could help guide the development of health services, their voices have not been heard. The experiences and perceptions of Inuit themselves are often overlooked in research. In this study, Inuit living in a small rural Arctic community on Baffin Island were invited to share their experiences of living with diabetes.

**Methods:** A qualitative multi-case study approach was taken. In-depth interviews (n=4), field observations, and informal interviews over one month in the community were used to build and contextualize the cases. In-depth interviews were transcribed, and analyzed using holistic thematic analysis and open coding.

**Results:** Accessibility was a concern with respect to foods, health knowledge, language interpretation and health services. In all methods of analysis, the importance of language and effective cross-cultural communication figured prominently. It was also evident that trust and rapport is crucial when discussing diabetes. There was strong interest in promoting diabetes education and prevention within the community.

**Interpretation:** These findings suggest that current health education and services may not be adequate for this setting. The voices of Inuit should be integral in steering the direction of their future diabetes education and health service delivery. Focusing on language barriers may help to improve the accessibility of knowledge about diabetes and nutrition, and enhance relationships between non-Inuit health service providers and Inuit.

**Key words:** Storytelling; Inuit; diabetes; language; access; health services

*La traduction du résumé se trouve à la fin de l'article.*

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For a person living with diabetes, experiences with food and health services are fundamentally linked with health outcomes. Indigenous people's dietary choices, which often now include both traditional and market foods, are influenced by societal, individual, socio-economic, and environmental factors.<sup>1</sup> These and the recent changes in Inuit lifestyles have stimulated health research within Inuit culture. Although the experience of living with diabetes in some Aboriginal populations has been explored, the voices of Inuit living with diabetes in Canadian Arctic communities have not been thoroughly represented in previous research.<sup>2-7</sup>

Currently, a high turnover rate of health care employees in Nunavut coupled with a lack of Inuit nurses and/or nurses who are fluent in Inuktitut have been identified as a challenge to providing culturally appropriate and acceptable health services.<sup>9,10</sup> Gaining insight into the food and health values and beliefs of Inuit is essential to develop a deeper understanding of their experiences with diabetes and its management in order to improve health service delivery and public health efforts.<sup>1,7</sup>

The purpose of this study was to explore the experience of four adult members of a small Arctic community who are living with diabetes. We investigated the factors that influence their food choices and perceptions of diabetes and health management.

Although it was in no way comprehensive, a holistic view of the Inuit health determinants was desired and thus, key concepts used to frame the issues and experiences of the storytellers included culture, place, and accessibility.<sup>1,11</sup> The relevance of these concepts to Inuit health has been established previously.<sup>11-21</sup>

### METHODS

The study was initiated at the request of a community member. Approval was granted from the governing Hamlet, and a working relationship was established between community members and the Centre for Indigenous Peoples' Nutrition and Environment (CINE).

The study was approved by a McGill University ethics review committee. A research licence was obtained from the Nunavut Research Institute, and a research

agreement was completed between the community and CINE following participatory research procedures.<sup>22</sup> Before participating, all storytellers signed an informed consent form. To respect, the confidentiality of storytellers, pseudonyms were assigned. At the end of the project, storytellers were contacted again by a member of the community research steering committee. Each storyteller was given a chance to review and make changes to a translated summary of the project and their individual quotes. Everyone renewed their consent to participate.

The study was conducted in an Arctic community on Baffin Island, Nunavut with a population under 1,300 people. Inuit who had Type 2 diabetes mellitus for a minimum of five years and had been prescribed oral anti-hyperglycemic medications were recruited through the community health centre and through a health-screening program.

The target sample size for the multiple case studies was four, which is considered optimal to facilitate in-depth interpretation of the data.<sup>23</sup> All interviews were conducted privately at a community building. A community member conducted and interpreted three of the one-hour interviews (in Inuktitut). One interview was conducted in English by the researcher. One female and three male elders participated. Due to the small sample, no gender-based analysis was conducted.

A list of open-ended questions was prepared to guide the interviews and was finalized by key informant community members and by a traditional knowledge expert with the Government of Nunavut Health and Social Service (see Table I).<sup>24,25</sup> Storytellers were encouraged to tell the story of their diabetes.

All interviews were recorded, and an oral translation was recorded by the interpreter within two days of the interview. The researcher transcribed the English interpretation. The Inuktitut recording was replayed for the interpreter to verify the accuracy of the English transcript. The researchers acknowledged that interpretation threatens the cultural competence of interviews.<sup>26-28</sup> To improve credibility, a second blinded community research assistant audited a recorded Inuktitut interview.<sup>23</sup> The two interpreters' English transcripts were compared by the researcher

**TABLE I**  
**Selection of Questions for In-depth Interviews**

1. Tell me the story of the day you found out about your high blood sugar. (Where were you, who were you with, what were you told, by whom, who did you talk to?)
2. How is your life different since you found out that you have diabetes?
3. What can a person do to manage their blood sugar?
4. Have you made changes in your life to control/manage your blood sugar? (Example: meds, diet, activity)
5. Describe which foods make you feel best?
6. How often are you able to have these foods?
7. Are you able to have the foods that you need to feel healthy?
8. What is it like to avoid foods that you once enjoyed?
9. Who would you trust most to give you information about high blood sugar?
10. Have you discussed high blood sugar with your family?
11. What is Inuit Qaujimajatuqangit (IQ)?
12. Are there any guiding principles from IQ that help you live with diabetes?

and a colleague and showed reasonable agreement.

The researcher kept a journal and recorded field notes while in the community.<sup>29</sup> She made observations at community events and conducted informal interviews with community members. Her journal entries included notes on her biases as a southerner visiting and conducting research in the north for the first time. Observations and notes were triangulated with the formal interviews to support the identification of themes.<sup>23,30</sup>

The stories were individually examined using a holistic thematic approach (full transcripts were repeatedly reviewed and themes were identified). Stories were also compared using manual open coding (a method of sorting data into categories relevant to the research topic to identify themes).<sup>31</sup> Different methods of interpretation and analysis involving different perspectives and different people were desired as a means of triangulation. To improve credibility, colleagues were asked to code and categorize passages of data to verify the researcher's analysis during the coding process, and two external qualitative researchers discussed the data analysis strategies with the researcher during the research process.<sup>23</sup>

## RESULTS

Despite the unique experiences and personalities of each of the storytellers, they shared many similarities (see Table II). All storytellers described diabetes as a relatively new phenomenon among Inuit. No one had heard a lot about diabetes prior to being diagnosed. Close family members were considered the best sources of social and emotional support. Talking, listening, and food sharing were described most often as examples of social support.

All storytellers described noticing physical and emotional changes in their daily lives with diabetes. Almost all expressed that they know their body best, thus they listen to others but often make decisions based on what their own bodies tell them.

The storytellers differed from each other in several ways. One person had only discussed diabetes with one close family member and health care providers. Another person has been very open to publicly discuss diabetes. There was a range of levels of independence among storytellers regarding their health care decisions. Two storytellers made some of their own choices about medication regimes and blood sugar monitoring while a third reported exclusive reliance on their health care team for direction. This suggests that there were varying levels of confidence and knowledge about diabetes. There were mixed sentiments about experiences with the "Southern" style of health care. Distrust and skepticism towards "Southern health care," was countered by other reports of trust and respect.

### Diabetes educational needs

The reluctance of three of the four storytellers to discuss diabetes openly within the community suggests that it is a stigmatized illness that is often poorly understood. This concern was supported when a community member asked if a person could develop diabetes after receiving a blood transfusion. Another storyteller mentioned that someone had asked him whether diabetes is sexually transmitted.

There was also frequent uncertainty about details of diabetes management, including proper monitoring of blood sugars, carbohydrate choices, and meal spacing. Some individuals demonstrated knowledge of target blood sugar levels, yet

**TABLE II**  
**Observed Themes with Relevance to Health Behaviours**

Accessing healthy foods was a frequent concern	<ul style="list-style-type: none"> <li>• “A Nutritionist has told me to eat certain foods, if I can eat those [market] food(s) everyday it would be best, but as Inuit we cannot always afford those foods we can eat from the grocery stores.”</li> <li>• “Seal meat, that’s what I would very [much] prefer. And I know it does help me...seal is... not readily always available, but it’s there, and I think it is due to that, because they have so many of us Inuit - due [to the fact] that’s our... main diet food. And so we prefer to have that, so it might not be more common to share with other people. But it is shared again, but not as much like fish or caribou.”</li> <li>• Informal discussion with community members revealed that in the past five years, they have noted changes in their climate. This is affecting their ability to predict the patterns of the animals and to hunt traditional foods. Consequently these changes will impact many people in the community, particularly those who rely on others to share traditional food.</li> <li>• A high cost of living was observed; this included the cost of market foods. We observed that fresh produce was three times the price of produce available in the South (Montreal).</li> <li>• Challenges with availability of fresh food and food spoilage was observed in the grocery stores by the researchers.</li> </ul>
Language and literacy pose challenges	<ul style="list-style-type: none"> <li>• “Going to the market I am unsure, to the grocery store. I am unsure what the product has in it - the nutritional facts [are in English] so I can’t really read that and that can’t really help me to understand what I am eating. ... I’ve seen photos of good food, but sometimes I forget what they look like and what they are.”</li> <li>• “Written information in Inuktitut should be really brought out to our communities so we could learn more about diabetes, how to prevent it, how to go about it cause for us people who don’t speak English, it’s really hard for us to prevent it.”</li> <li>• The researchers observed all signage in the grocery stores was exclusively English.</li> </ul>
Cross-cultural communication is challenging	<ul style="list-style-type: none"> <li>• “The nurse asked me if I drink a lot in a day, I replied “yes I drink a lot and I make sure I drink a few times a day and also during the night”. He was then very concerned because when he asked that question I didn’t know he meant drinking alcohol. I told him “no I don’t drink any of that, I thought you meant water”. We started laughing over that.”</li> </ul>
Country food (traditional food) is valued	<ul style="list-style-type: none"> <li>• “All my life I eat country food and I prefer country food. Everyday I eat country foods... country food is the best food... What I live for.”</li> <li>• “Always eating country foods we will never get tired of eating those foods, what foods we crave is what we are given. A person who is craving for - he will eat and he will get better if he’s sick and that’s a guarantee.”</li> </ul>

maintained higher levels. This suggests that while sharing knowledge is important, health educators should also try to understand and address the factors that motivate their patients.

**Inuit need their own framework to explain health and wellness**

Prior to visiting the community, various models that might help to explain certain health behaviours regarding diabetes were considered. Most models, however, were rooted in “Southern” public health and medical beliefs and have been less helpful to understand Aboriginal peoples’ health (Health Belief Model, Social Cognitive Theory, and the Theory of Reasoned Action).<sup>32,33</sup> The challenges of applying models rooted in “Southern” medical traditions, and the documented culturally sensitive approaches needed to provide health services to Inuit, led the researchers to seek a more Inuit-specific framework.<sup>21</sup> The Inuit Qaujimagatuqangit (IQ) was explored as a vehicle to understand motivation and health-seeking behaviours. It became clear that IQ is understood in numerous different ways. For example, the Nunavut Social Development Council declared in 1999 that, “IQ is all aspects of our culture...all aspects of traditional Inuit culture including values, world-view, language, life skills, perceptions and expectations”.<sup>34</sup> However, IQ is also understood by some to pertain exclusively to animal-human relations and the land (environment).<sup>34</sup> IQ can also be used to guide

social relationships. When asked about the IQ (see Table I), none of the storytellers reported finding guidance directly from IQ to live well with diabetes. Furthermore, IQ may be viewed as static (ancient knowledge) by some, and not helpful to deal with diabetes, which is considered a relatively new disease. Although it has not been explored, perhaps the IQ principles that shape social relationships indirectly influence the behaviours of Inuit living with diabetes.

Alternatively, determinants of health frameworks have been recommended as an appropriate way to broaden understanding of Aboriginal Peoples’ health because it utilizes a holistic view of well-being.<sup>1,11,35</sup> Upon examining determinants of healthy eating in Aboriginal Peoples in Canada, Willows reports major gaps in the literature.<sup>1</sup> Furthermore, Hanrahan identifies that Innu and Inuit patients in Newfoundland perceive language and communication as a major barrier to delivering health services.<sup>7</sup> He concludes, “Until these issues are addressed, it is virtually impossible for health care practitioners to understand, say, how Aboriginal people socially construct their illnesses.”<sup>7</sup> The Inuit Tapiriit Kanatami has collaborated with other Inuit networks and committees to lobby the Canadian government for an Inuit-specific diabetes framework that recognizes the dynamic nature of Inuit culture.<sup>36</sup> The themes identified in the storytellers’ narratives have illustrated the ways that Inuit in this community have acted in

response to their health situation: by learning about illness, gaining coping strategies, and actively sharing knowledge. Recognizing these adaptive characteristics may enhance outsiders’ sensitivity and reinforce the importance of an Inuit diabetes framework.

**DISCUSSION**

The various methods used to examine the stories reveal similar themes and issues (see Table III). Of concern is that gaining access to traditional food may be beyond the power/capability of some community members living with diabetes. One storyteller suggested requesting financial assistance from social services to enable people with diabetes to afford more healthy market and country foods.

Limitations of this research include that one might question how comfortable all storytellers felt about sharing their stories with outsiders. Anxiety about discussing a personal topic, and the researcher’s background as an outside professional (dietitian) may have influenced their responses.<sup>37</sup> Furthermore, the language barrier posed a continual challenge to effective communication. On the other hand, it was a strength that the project was requested and approved by the community and all participants decided to allow for publication of their translated interview segments and report summary prior to publication. Throughout the study, the comfort and confidentiality of the storytellers remained

**TABLE III**  
**Ways in Which Some Inuit Have Adapted to Living with Diabetes**

Self awareness	<ul style="list-style-type: none"> <li>• “Each individual like myself we know exactly how our body works and we know we are hurting. When we go to the hospital they seem to never find out what’s wrong with us when we know what’s wrong with us. Because this is my body I know where I’m hurting this is where I have my pains...”</li> <li>• “That time when I was first told, I had great eye vision, this is how I was, that’s cause when you’re told you don’t have any illness that is how you are. After being told I had gotten diabetes I have seen a lot of changes...”</li> <li>• “The best [blood sugar] range to be at is 4, 5, and 6 even though that can be a little high, number 4 is the best range, but I make sure that it doesn’t go any lower because when it does I have to eat a piece of candy in order to bring back my sugar level. I know when my sugar level gets lower when my physical body is giving me signs such as shaking, my body becoming really weak, and then I check my sugar level to find out where I am standing at, so when it goes to 3 or 2, it gets really scary, my body changes all the time.”</li> </ul>
Issues with trust and rapport	<ul style="list-style-type: none"> <li>• “I have heard in the past that people who talk back or people who don’t communicate with their nurses properly because of being negative or other such things in that nature are not allowed to see nurses if they are going to have negative responses to them.”</li> </ul>
Skepticism towards health care and outsiders	<ul style="list-style-type: none"> <li>• “I don’t mind talking about diabetes but, being a diabetic it’s really hard. If we had more people out there to talk about diabetes it’d be a lot easier as patients for us people who do have sicknesses. Should have a person who [we] can talk to about our sicknesses, not only just to tell them but also for them to teach us about and also to give us answers to the questions that we have, I mean we could always go to the doctors or nurses but they’re going to give us Tylenol and that’s about it.”</li> <li>• “Only when the doctors and nurses who specialize in that area started arriving into Inuit communities, this is when I think Inuit started having diabetes...we seem to get sick only when non-Inuit people came into town for different purposes.”</li> </ul>
Diabetes and identity	<ul style="list-style-type: none"> <li>• “I don’t always go straight forward and talk to people [in the community] about it [diabetes] I mean, I sort of hint it out but not really tell anyone and a lot of them don’t believe in you, they don’t believe that you have diabetes or they think you’re just saying it to, I don’t know, just to really show that you have it, or to show that you are sick or, in a way of a showing off.”</li> <li>• “I am the same person as I was when I did not have diabetes I will never change, just because I have diabetes it does not mean I am any different.”</li> </ul>
Coping strategies	<ul style="list-style-type: none"> <li>• “I believe eating country food is the best way to help my body compared to market foods. Never eating country foods for a while makes you get really lazy, and makes you want to eat more and more market foods.”</li> <li>• “I got to watch what I eat all the time. You see um, that, see I try to have oatmeal that’s my, seems to be my biggest thing to me, you see ah, mornings. That – if I can have my oatmeal than I’m gonna be alright. And I know that I’m gonna be alright in that morning, and that’s gonna give, because that doesn’t really give me a lot of crave for to eat in middle and whatnot, so my oatmeal is the, I would say is the best for me.”</li> <li>• “I don’t know how to exercise with any exercising equipment, but I try doing other stuff such as, cleaning and walking... I do this so I can help my body so I can be healthy.”</li> <li>• Regarding accepting diabetes: “It’s, mentally, it was ah, it was very hard. And knowing what can be, what it can happen to you. And then there after, the more I did research on it, that you can control it – that you can do it. And so that’s where I took that, and now you see ah, what I tried to do, you see ah, controlling it daily. One day at a time of course, and then, and from there I just to keep think positive of what I have to go through daily.”</li> </ul>
Sharing knowledge is empowering	<ul style="list-style-type: none"> <li>• “My philosophy is if I have it (diabetes), when I share it, so they can see it, so they can have a knowledge about it, about my disease... if I can share it with other people, especially that are younger than me, that if I can share it with those people at least I am giving my knowledge about my disease to that person, so that person can do a prevention if he wants or she wants and so you see ah, what I want is [to] ..., use my diabetes, what I have ... so that it can be used by other people for prevention because they’ll have understanding about it.”</li> </ul>

the priority. Steps taken to increase the rigor and credibility of the work described earlier include: triangulation of multiple methods, member checking of transcripts, and peer verification of coding.

The strong desire for diabetes education and support coupled with skepticism towards outsiders present Inuit and their non-Inuit health service providers with many complicated challenges. Storytellers suggested that it would be helpful to form a support group in the community for people already diagnosed with diabetes and their immediate families. Inuit have their own knowledge – their voices should be integral in steering the direction of their future diabetes education and health service delivery. Addressing language barriers may help to increase the accessibility of knowledge about diabetes and nutrition, and improve relationships between non-Inuit health service providers (including doctors, nurses, and nutritionists) and Inuit.

The current and previous research<sup>4-8</sup> speak to the value of storytelling as a

means of providing relevant context for improving our understanding of diabetes in Aboriginal communities. Also, storytelling is an invaluable tool in designing health care delivery models and health promotion campaigns that are culturally acceptable and relevant. For Inuit, language barriers featured prominently in interviews concerning diabetes education, health food choices, and health care delivery. Tungasuvvingat Inuit, with the permission of The Canadian Diabetes Association, has now developed educational materials in Inuktitut, which is a step forward in addressing the concerns of the Inuit storytellers.<sup>38</sup>

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**RÉSUMÉ**

**Contexte :** La prévention et la prise en charge du diabète de type II deviennent préoccupantes dans les communautés inuites du Canada. Les Inuits diabétiques qui vivent dans les communautés éloignées de l'Arctique canadien pourraient contribuer à l'élaboration des services de santé qui leur sont destinés, mais leurs voix ne sont pas entendues. L'expérience et les perceptions des Inuits eux-mêmes sont souvent négligées par la recherche. Nous avons donc invité des Inuits vivant dans une petite communauté rurale arctique de l'île de Baffin à partager leur expérience du diabète.

**Méthode :** Nous avons effectué une étude qualitative de plusieurs cas. Des entretiens en profondeur (n=4), des observations sur le terrain et des entretiens informels se sont déroulés dans la communauté sur une période d'un mois afin d'étayer les cas et de les mettre en contexte. Les entretiens en profondeur ont été transcrits et analysés selon une méthode d'analyse thématique holistique et un mode de codage ouvert.

**Résultats :** L'accessibilité aux aliments, aux connaissances sur la santé, à l'interprétation linguistique et aux services de santé est problématique. Quelle que soit la méthode d'analyse, l'importance de la langue et les communications transculturelles efficaces figurent au premier plan des préoccupations. Il est clair aussi que la confiance et le lien avec le patient sont des éléments cruciaux lorsqu'on discute du diabète. Les membres de la communauté se sont montrés très intéressés à promouvoir l'information et la prévention en matière de diabète.

**Interprétation :** Il semble que l'information et les services sanitaires actuels laissent à désirer dans le milieu à l'étude. Les voix des Inuits devraient être entendues lorsqu'on s'efforce de déterminer les orientations futures de l'information et de la prestation des soins du diabète. En s'attaquant aux barrières linguistiques, il serait possible d'améliorer l'accès aux connaissances sur le diabète et la nutrition et de bonifier les relations entre les Inuits et le personnel soignant non inuit.

**Mots clés :** récits; Inuits; diabète; langue; accès; services de santé