Living with Diabetes on Baffin Island
Inuit Storytellers Share Their Experiences

Susan M. Bird, MSc(A)1
Janine L. Wiles, PhD2
Loosee Okalik3
Jonah Kilabuk4
Grace M. Egeland, PhD1

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.

1. Department of Agriculture and Environmental Science, School of Dietetics and Human Nutrition, Centre for Indigenous Peoples’ Nutrition and the Environment (CINE), Macdonald Campus of McGill University, Ste-Anne-de Bellevue, QC
2. School of Population Health, University of Auckland, Auckland, New Zealand
3. Health Projects Coordinator, Inuit Tapiriit Kanatami, Ottawa, ON
4. Project Steering Committee Member, Baffin Region, Canada

Correspondence and reprint requests: Dr. Grace Egeland, CINE, Macdonald Campus of McGill University, 21, 111 Lakeshore Road, Ste-Anne-de Bellevue, QC H9X 3V9, Tel: 514-398-7757, Fax: 514-398-1020, E-mail: grace.egeland@mcgill.ca

Acknowledgements: This project was supported by the McGill Max Bell Foundation, and a grant from SSHRC. The authors thank Emily Karpik for translations and interviews and Guylaine Charbonneau-Roberts for assistance in the field.

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. Before participating, all storytellers signed informed consent form. To respect, 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. All interviews were conducted privately at a community building. A community member conducted and interpreted three of the one-hour interviews (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). 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. To improve credibility, a second blinded community research assistant audited a recorded Inuktitut interview. The two interpreters’ English transcripts were compared by the researcher and a colleague and showed reasonable agreement.

The researcher kept a journal and recorded field notes while in the community. She made observations at community events and conducted informal interviews with community members. Her journal entries included notes on her biases with the formal interviews to support the identification of themes.

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). 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.

RESULTS

Despite the unique experiences and personalities of each of the storytellers, they shared many similarities (see Table I). 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
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). 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. The Inuit Qaujimajatuqangit (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”. However, IQ is also understood by some to pertain exclusively to animal-human relations and the land (environment). 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. Upon examining determinants of healthy eating in Aboriginal Peoples in Canada, Willows reports major gaps in the literature. Furthermore, Hanrahan identifies that Innu and Inuit patients in Newfoundland perceive language and communication as a major barrier to delivering health services. 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.” 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. 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. 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
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 own knowledge – their voices should be integral in steering the direction of their health practice and belief.

The current and previous research 1-8 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. 38

REFERENCES

INUIT STORYTELLING ON LIVING WITH DIABETES


RECEIVED: September 20, 2006
ACCEPTED: June 22, 2007

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 négliguées 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’êtayer 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