

DIABETES BINGO! USING PARTICIPATORY RESEARCH TO TACKLE DIABETES WITH THE ALGONQUIN OF BARRIERE LAKE

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ABSTRACT

Aboriginal peoples in Canada are currently facing high rates of chronic and infectious diseases. The incidence of type 2 diabetes among this population has been described as an “epidemic.” To address this growing problem, community health researchers are calling for participatory research initiatives and culturally adapted, community-based health promotion interventions. Employing a participatory approach with the Algonquin community in Rapid Lake, the purpose of this research project was to design and implement a sustainable, culturally adapted, health promotion intervention for young to middle-aged community members diagnosed with type 2 diabetes and their families, in Rapid Lake, Québec. Over three and a half months, a focused ethnography was conducted using key informant interviews, focus groups, and participant observation. Analysis was an iterative process with input from academic supervisors and a community health representative (CHR). Three themes were identified: (1) *Minimadizuin*, a holistic concept of health and well-being in Algonquin culture, underlies community members’ understanding of diabetes; (2) local knowledge of diabetes is mediated through experiences with the illness; and (3) community members are eager to learn about diabetes and health-promoting strategies. Outcomes of the research project included the development of an educational activity and a workshop series. Application of participatory research principles, including the integral involvement of the CHR as a research partner, facilitated the development of a sustainable health promotion intervention adapted to the local and cultural context of Rapid Lake.

Keywords: participatory research, Aboriginal, diabetes, community health promotion

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INTRODUCTION

Aboriginal communities are currently confronting high rates of infectious diseases such as tuberculosis, and chronic diseases such as cardiovascular disease, certain cancers, and type 2 diabetes (Anderson et al., 2006; Young et al., 2000; Willows, 2005). Many of these health issues have a higher incidence rate among Aboriginal communities, and type 2 diabetes in particular has been described as an “epidemic” with an earlier age of onset in Aboriginal communities than the Canadian non-Aboriginal population (Barton et al., 2005; Hernandez et al., 1999; Macaulay et al., 2003). Addressing this health concern in Aboriginal communities requires health promotion interventions that incorporate local perceptions of health and diabetes and are culturally adapted and community-based (Boston et al., 1997; Macaulay et al., 2003).

Over the past five years, the McGill School of Nursing has developed a research partnership with the Algonquin of Barriere Lake who reside in Rapid Lake, Québec. Each year, a research project has been initiated by a McGill Masters of Nursing student in partnership with the community, aiming to create sustainable health promotion interventions and enhance knowledge sharing between this Algonquin community and the McGill School of Nursing. The purpose of the 2011 project was to work with the community to design and implement a sustainable and culturally adapted health promotion intervention for young to middle-aged community members diagnosed with type 2 diabetes and their families. The project was implemented in partnership with the local community health representative (CHR) and supervised by two McGill supervisors and a

clinical supervisor from the Kitiganik Health Clinic in Rapid Lake.

LITERATURE REVIEW

CHANGES IN ABORIGINAL HEALTH STATUS

Prior to European colonization, Aboriginal peoples had low rates of illness and disease, and consumed a simple, nutritious, low fat diet (Royal Commission on Aboriginal Peoples [RCAP], 1996; Willow, 2005). The health status of Aboriginal people has since undergone many significant transitions, linked to exposure to virulent infectious diseases and colonialist policies leading to changes in subsistence patterns and manner of living. These processes have led to a current health status that is characterized by rates of infectious and chronic diseases that are higher than the non-Aboriginal population in Canada (Miller, 2002; RCAP, 1996). These chronic diseases include diabetes mellitus, cardiovascular diseases, and certain types of cancers (RCAP, 1996).

Diabetes mellitus is a metabolic disorder characterized by chronic hyperglycemia — often referred to as high blood sugar — due to defects in insulin secretion or action. Insulin is a hormone that plays a key role in regulating blood sugar. Multiple types of diabetes exist, the most common being type 1 and type 2 diabetes. In type 1 diabetes, high blood sugar results from the destruction of cells located in the pancreas that produce and release insulin (American Diabetes Association [ADA], 2004). Type 1 diabetes is an autoimmune disorder and the age of onset is often during childhood, but can occur later in life as well. Type 2 diabetes results from a defect in insulin action and secretion due to insulin resistance, making the insulin hormone less effective at controlling the body's blood sugar level (Canadian Diabetes Association Clinical Practice Guidelines Expert Committee [CDACPGEC], 2008). Insulin resistance is associated with obesity and decreased physical activity (ADA, 2004). Although type 2 diabetes is commonly characterized as a disease occurring in middle-aged and older adults, there is a recent trend towards an earlier age of onset (Alberti et al., 2004).

Chronic hyperglycemia (high blood sugar) is related to dysfunction and failure of various organs, particularly of the eyes and kidneys, and the de-

velopment of neuropathy. Further, diabetes increases the individual's risk of developing cardiovascular, peripheral vascular, and cerebrovascular diseases, such as hyperlipidemia, hypertension, myocardial infarctions, and atherosclerosis (CDACPGEC, 2008). Health complications associated with diabetes include lower extremity amputation, adult blindness, and end-stage renal disease. Research has demonstrated that the rate of diabetes-associated complications is strongly associated with the length of time living with the illness. An earlier age of onset may result in an increase in these complications (CDACPGEC, 2008; Young et al., 2000).

Within the past 60 years, the incidence of type 2 diabetes has been described as reaching “epidemic” proportions amongst Aboriginal peoples (Young et al., 2000), with an estimated incidence three to five times greater than the general Canadian population (Health Canada, 2010). Of particular concern is the decreasing age of onset amongst this population, evidenced in the rising incidence of type 2 diabetes among Aboriginal children and youths. With this decreased age of onset, women of child-bearing age are increasingly likely to develop type 2 diabetes prior to and during pregnancy, referred to as gestational diabetes. As gestational diabetes is linked to the woman's biological children developing diabetes, this increases the risk of type 2 diabetes for future generations (Barton et al., 2005; Hanley et al., 2003; Macaulay et al., 2003; Young et al., 2000).

According to Dannenbaum and colleagues (2008, p. 47):

this striking increased prevalence of diabetes is likely due to a combination of genetic susceptibility and a relatively rapid change from active bush living to a more sedentary modern lifestyle.

The rapid sociocultural changes in Aboriginal cultures resulting from contact with European colonists has created a shift from a hunter-gatherer subsistence system to a more sedentary lifestyle, with a subsequent decrease in traditional activities and forms of exercise. Furthermore, dietary acculturation has been described in the literature, involving a shift from consuming traditional foods, such as wild game, to “modern” foods which have lower nutritional value in that they are high in refined

carbohydrates and fat (Anand et al., 2001; Chateau-Degat et al., 2009; Reading and Wein, 2009; Young et al., 2000).

ABORIGINAL PERCEPTIONS OF HEALTH AND DIABETES

Aboriginal peoples understand health from within their unique histories and cultures; these understandings often differ from a Western biomedical perspective (Adelson, 1998). A common element described across many Aboriginal cultures views health as more than the biophysical aspects of the body. This involves a balance among multiple aspects of the individual: the body, the mind, emotions, and the spirit. These individual aspects are interconnected and deeply linked to the sociocultural and physical environment, including family, community, and the land (Kooiman et al., 2012; RCAP, 1996).

This understanding of health is reflected in Aboriginal peoples' knowledge of diabetes. Research has been undertaken with various Aboriginal communities to explore their understanding of diabetes. Several themes have emerged within this literature, including perceiving diabetes as a “white man's illness” (Young et al., 2000), related to colonialist policies and the “destruction of Indian society” (Hernandez et al., 1999, p. 221). Aboriginal peoples link ways of living and diabetes, relating the high incidence of diabetes to a shift from traditional ways of living (Hernandez et al., 1999). Among the James Bay Cree, this conceptualization of diabetes extends to its treatment: going “into the bush” is viewed as part of the healing process (Boston et al., 1997).

DIABETES INITIATIVES IN ABORIGINAL COMMUNITIES

The need for community-based initiatives to address the growing incidence of type 2 diabetes has been well recognized. According to the literature, initiatives must be culturally adapted for the local Aboriginal community, incorporating local conceptualizations of health (Bisset et al., 2004; Boston et al. 1997; Dannenbaum et al., 2008; Macaulay et al., 2003). Various initiatives have been developed, including the Aboriginal Diabetes Initiative (ADI) which was established in Canada in 1999 in an effort to address this national health concern. As part

of ADI, trained community workers deliver diabetes prevention and health promotion activities and services in Aboriginal communities (Health Canada, 2010). The Kahnawake Schools Diabetes Prevention Project (KSDPP) and the Sandy Lake Health and Diabetes Project (SLHDP) are two effective and sustainable initiatives employing a community-based participatory research (CBPR) framework (Macaulay et al., 2003).

SETTING: THE ALGONQUIN OF BARRIER LAKE, RAPID LAKE, QUÉBEC¹

The Algonquin of Barriere Lake have experienced much social and cultural disruption. For instance, many older residents in the community are residential school survivors, and the community moved from its traditional grounds near Barriere Lake to its current location with the establishment of a Hudson Bay trading post (J. Wawatie, personal communication, 7 November 2012). The community has also been coping with ongoing conflict with the Canadian federal and Québec provincial governments over resource use (Rusnak, 1997). This has provoked internal instability including the resignation of Chief Wawatie in 2006, thereby disrupting the community's traditional form of governance and patrilineal descent, the *Mitchikanibikok Anishinabe Onakinakewin*. A band council has since been elected, although disagreement remains over its legitimacy. These political tensions have led to a substantial division within the community (Sherman et al., 2011). The community is currently under third-party management due to a significant financial debt that jeopardizes the consistent delivery of essential social and health services to community members (Barriere Lake Solidarity, 2008; Indian and Northern Affairs Canada [INAC], 2010).

In Rapid Lake, there are high rates of unemployment and poverty, with an estimated unemployment rate of 80–90%. Most individuals in the community receive monthly social assistance payments and some are able to find seasonal employment. Many fam-

¹ Where a reference is missing, Laura Wakani, the student researcher, learned much of the history and knowledge of Rapid Lake and the Algonquin of Barriere Lake during personal communications with nursing and clinic staff, community members, and from living in the community.

ilies live in overcrowded, poorly maintained houses with inadequate infrastructure (Sherman et al., 2011). Within the community there is an elementary school, a police detachment, a volunteer fire department, a hockey rink and youth center co-ordinated by a Youth Worker. Youth who wish to attend high school must leave the community, boarding with family or friends in Maniwaki or Val D'Or, over 100 km away. The closest grocery store and service centre is approximately 130 km away (Sherman et al., 2011).

While the community has limited resources, the Kitiganik Health Clinic, funded and managed by Health Canada, is able to deliver multiple community health services. The clinic is staffed by four non-Aboriginal nurses, an Algonquin community health representative (CHR), an Algonquin youth worker, an Algonquin Maternal-Child Health (MCH) program coordinator and an Algonquin National Native Alcohol and Drug Abuse Program coordinator (NNADAP). Oral health services are available through the clinic by dentists and dental hygienists visiting approximately twice per month.

There is also a diabetes program run by a nurse at the clinic² and in 2009 a participatory research project developed a primary prevention program for youth in the community. In this project, researchers found that community youth possess impressive knowledge about type 2 diabetes and were keen to participate in interactive learning focused on diabetes prevention (Sherman et al., 2011). Building on these findings, the health care staff of the Kitiganik Health Clinic requested a future project to address type 2 diabetes for young adults due to the rising incidence observed in the community.

PROJECT OBJECTIVES

The objective of the research project was to work with the community to design and implement an intervention to promote health for young to middle-aged adults living with type 2 diabetes and their families. To achieve this objective, three central questions directed the research: (1) What are the challenges to achieving and sustaining health for young to middle-aged adults living with type 2 diabetes in Rapid Lake?

(2) According to community members, what types of interventions will best promote health among young to middle-aged adults living with type 2 diabetes and their families? (3) How can a participatory research framework enable the development of a sustainable health promotion intervention in Rapid Lake?

RESEARCH DESIGN

As part of the requirements for a Masters of Nursing degree, the research project was initiated and completed from September and December 2011, during which the student researcher was also completing a clinical placement at the Kitiganik Health Clinic. Focused ethnography was selected as the guiding methodology due to the project's timeframe, the size of the community, and the specifically focused health issue (Muecke, 1994). Focused ethnography has its origins in cultural anthropology, employing that discipline's classic methods of data collection. However, focused ethnography has a shorter time-scale and more limited focus of inquiry (Roper and Shapira, 2000). Data collection methods included participant observation, key informant interviews, and focus groups, allowing the researcher to gain a greater understanding of the health phenomenon under study and insight into the community members' perspective on this issue (Mack et al., 2005; Roper and Shapira, 2000). In ethnographic research, the researcher plays the role of both researcher and research instrument (Polit and Beck, 2008); thus, the student researcher facilitated the interviews, focus groups, and pilot program, and collected and analysed data iteratively using descriptive, analytical, methodological, and personal field notes and interview transcripts.

Academic research with Aboriginal peoples has a controversial past. Aboriginal peoples often have not been treated as equal partners in academic research projects (Cochran et al., 2008; Smith, 1999) which have focused on "Western 'ways of knowing' and are therefore inherently culturally insensitive" (Cochran et al., 2008, p. 23). Communities are now advocating for the use of methodologies that employ culturally adapted concepts and promote participant involvement in the project to "decolonize" the research process (Bartlett et al., 2007). Participatory research has been developed to address these concerns.

Participatory research achieves the objective of decolonizing research methodologies through three important processes: collaboration, mutual education, and action (Macaulay et al., 1999). Collaboration includes involving participants in the research process and establishing research partners from the community; mutual education in participatory research involves a sharing of knowledge among the research partners; and action must be based on the findings of the collaborative research partnership (Macaulay et al., 1999). To create such a collaborative partnership, we invited the CHR to become a research partner in our project given her unique role at the health clinic where she had been working for three years. As part of her mandate, she acts as a liaison between the community and staff of the clinic, providing health education, home visits with Elders, health promoting community events, and supporting clinic programs. Further, she has received extensive training in diabetes management and prevention education and provides support to the diabetes program facilitated by the diabetes nurse at the clinic.

We used Turton's (1997) health world view framework to ground our project. This conceptual frame encourages the exploration of local, culturally specific health knowledge and beliefs rather than privileging a Western biomedical perspective. The health world view framework is purposefully broad and acts as more of a guide for discovery than a theory. Thus, it allowed us to explore the meaning of health and type 2 diabetes among the Algonquin of Barriere Lake.

We used this framework in various ways. For example, it helped shaped our interview questions: we purposely led with questions that sought local ways of knowing about diabetes, including etiology, meaning, and impact; this can be compared to approaches that lead with biomedical definitions, theories of causation, or assumed repercussions. Further, this conceptual frame helped structure our participant observation by encouraging us to watch and listen for diabetes knowledge and experience in unconventional locations, such as when people connected inevitability with genetics, leading them to believe they were "doomed" to get diabetes. Finally,

it framed our data analysis, reminding us not to privilege biomedical assumptions but instead to explore how local meanings converge and diverge with scientific conceptions of the disease in important ways, and how health promotion must work carefully to bring together multiple world views.

The research project was divided into four phases. In Phase One, data collection occurred through key informant interviews and two focus groups with community members. Data collection was conducted by the student researcher following a semi-structured format with open-ended questions focusing on health and diabetes and also drawing on interview guides from previous research projects in Rapid Lake (Kooiman et al., 2012; Sherman et al., 2011). Questions addressed health and healthy ways of living, challenges to health, and diabetes and its impact on families and community. The questions were reviewed by the CHR to ensure their cultural relevancy and were adapted as the project progressed.

Key informants, defined as community members who could provide rich and detailed information concerning the topic at hand (Polit and Beck, 2008), included Elders, health care staff, community members diagnosed with diabetes or those with a family member diagnosed with diabetes. Key informants were identified with the aide of the CHR and the Kitiganik Health Clinic staff and were purposefully sampled (Polit and Beck, 2008) to ensure a variety of perspectives. Five key informants were interviewed, including four Algonquin community members and one member of the clinic nursing staff. The Algonquin key informants held varying roles in the community: two were community health workers, one was a former staff member of the clinic, and one was a member of the band council. Interviews were conducted at the clinic and lasted between 45–60 minutes.

Participants for the two focus groups were recruited through a snowball sampling method (Polit and Beck, 2008) based on the following criteria: community members, diagnosed with diabetes or with a family member diagnosed with diabetes. Potential participants were approached by clinic staff and asked to invite other community members who might be interested. Many potential partici-

² According to a personal communication with the Head Nurse of the Kitiganik Health Clinic, there currently is not an ADI representative in Rapid Lake; the existing diabetes program has been developed and implemented by a diabetes nurse.

pants were primary school staff. Because of their extensive interest, focus group #1 was held solely with the school staff, including teachers, administrative staff, custodians, and cooks; it was a heterogeneous group of 11 individuals who had and had not been diagnosed with type 2 diabetes. It lasted 35 minutes and was held at the Kitiganik Health Clinic.

Recruitment for focus group #2 was similar. Four community members were identified by clinic staff members, two of whom had been diagnosed with type 2 diabetes and two who had family members diagnosed with diabetes. The participants held varying roles and positions in the community (e.g., mother, hunter, former staff of the clinic, and part-time staff at the school). It was conducted at the Kitiganik Health Clinic. The CHR was present at both focus groups to ensure participants could speak Algonquin if they preferred.

Phase Two was the development of a health promotion pilot program based on the outcomes of the data analysis from Phase One. The program was an educational version of "Bingo" that provided information on type 2 diabetes (see Appendix A for example of Diabetes Bingo! Card). The activity was advertised to the community through word of mouth, by nurses at the clinic and during the National Aboriginal Addictions Awareness Week held at the clinic. All adult community members were welcome to participate. Participants were asked to provide written feedback anonymously.

Phase Three of the project was adapting the pilot program. Responding to participant feedback and data analysis, an educational workshop series was developed. Phase Four was a presentation to the community of the findings and outcomes of the project. The presentation was open to all community members and advertised through word of mouth. At the presentation, anonymous written feedback was gathered from community members.

Data analysis was an iterative process conducted throughout the four phases by the student researcher with continual input from the CHR and the McGill supervisors. Data collected from key informant interviews, focus groups, and participant observation field notes were analyzed thematically and representative verbatim quotations were com-

pared to support each emergent theme. The themes from each data source were then compared across data sources to establish common as well as contradicting themes and to establish overarching themes with subthemes. These themes and subthemes were then discussed with the CHR who helped to interpret the preliminary analysis from her perspective as a community member. Three overarching principle themes with subthemes were agreed on.

Multiple processes were employed to ensure methodological rigour. Data triangulation was established through the use of multiple data sources (participant observation, interviews, focus groups, written and oral feedback). Transferability of the findings was established through detailed descriptions of setting, participants, and project outcomes. The reflexivity of the student researcher was maintained through personal field notes concerning values and personal biases, which were shared with the McGill supervisors (Graneheim and Lundman, 2004; Polit and Beck, 2008; Roper and Shapira, 2000). The student researcher maintained weekly contact with McGill supervisors, providing an audit trail on all data collected.

Prior to starting the research project, ethical approval was received from the Institutional Review Board of the McGill University Faculty of Medicine. Written informed consent was obtained prior to conducting interviews and focus groups and oral informed consent was obtained prior to the pilot program and the community presentation.

FINDINGS

Three principle themes were identified: (1) *minimadizuin*, a holistic concept of health and well-being in Algonquin culture, underlies community members' understanding of diabetes; (2) local knowledge of diabetes is mediated through experiences with the illness; (3) community members are eager to learn about diabetes and health promotion strategies.

Theme #1: Minimadizuin, a holistic concept of health and well-being in Algonquin culture, underlies community members' understanding of diabetes

During key informant interviews and focus groups, the Algonquin conceptualization of health, *minimadizuin*, was often discussed. Community

members explained that this term expresses more than a biophysical definition of health; it involves taking care of the mental, emotional, spiritual, and physical aspects of the self. In particular, *minimadizuin* involves a ways of living that allows one to find a balance between these interrelated aspects of the self. Community members described a manner of living that achieves this balance as "healthy" or "living well." When discussing the Algonquin conceptualization of health, one community member, a teacher from the local elementary school, described finding this balance:

Healthy person would be feeding your spirit, every aspect of yourself; so you're feeding your spirit, praying or anything that you do, you know? Just all four aspects of yourself and making sure they're all balanced, whether it be the physical, emotional, mental.... Just making sure that you're balanced in all areas, would be a healthy lifestyle.

Minimadizuin involves caring for oneself, one's family, and community. In describing the meaning of *minimadizuin*, a community worker explained it this way: "Healthy family ... taking care of yourself, taking good care of your kids, eating well." Another participant, herself diagnosed with type 2 diabetes and self-identified as a role model for other families, described health as: "Sober, eating right, active lifestyle ... going for a walk, taking the baby for a walk, playing with your kids, taking them to the park, getting involved with them." These testimonies demonstrate that within Algonquin culture, an individual's health and the family's health overlap. Further, as the above quote highlights, the relationship between alcohol use and health is important; when asked to describe healthy living, another community member said: "Healthy living would be no drinking, well moderate drinking, with moderate drugs." Sobriety or limited alcohol use were repeatedly identified as part of a healthy manner of living whereas alcohol and drug use was identified as a barrier to achieving health.

Food and activity also represent important aspects of *minimadizuin*. According to community members, health is promoted through a traditional manner of living which involves participating in traditional activities and eating traditional foods. As one

participant described when discussing *minimadizuin*, "it sums it all up, living well ... eating well, living healthy." Traditional foods were identified as healthy, including items such as moose meat, fish, beaver, partridge, wild rice, and fiddleheads. Nontraditional activities, such as hockey and volleyball, and foods, including various fruits and vegetables, were also described as healthy, although traditional foods and activities were preferred.

Traditional activities such as canoeing, walking, and snowshoeing are important given that historically they were how traditional foods were collected. Currently, there is increasing difficulty in obtaining traditional foods due to deforestation and environmental change as one participant explained:

See a lot of fish that are sick, and moose, animals are getting sick because of pollution I guess, because there's too many clear cuts ... there's less and less [animals]. Before that you didn't have to go far to get a moose, now you have to go far.

Such changes have led to an increased reliance on boats and all-terrain vehicles for hunting, as opposed to traditional forms of activity.

Throughout the research project, the CHR interpreted local perspectives on health, *minimadizuin*, diabetes, and effective interventions. For instance, she explained that any interventions to promote health must incorporate *minimadizuin* as well as biophysical aspects of health. A walking group that involved people coming together, walking in the bush, and checking snares and trap lines was used as an example. Walking addresses the physical self, being in the bush addresses the spiritual self, and socializing can address both the mental and emotional aspects of the self, all components of *minimadizuin*.

Theme #2: Local knowledge of diabetes is mediated through experiences with the illness

Throughout the interviews and focus groups, it was evident that participants had a wealth of knowledge of diabetes through their many years of experience with the illness. Local knowledge of diabetes was mediated through personal experiences and, especially, experiences with family members diagnosed with diabetes. One key informant described her experience of being diagnosed with diabetes:

Like for everybody else, when I first found out I was diabetic I was shocked ... it was a big shock for me. Now I'm ok. [When first found out I thought] I had to go to dialysis, amputations.... I knew because my mom had diabetes and she had complications of diabetes, she had amputations of toe, finger and was on dialysis for eleven years. But that was before I took my course, I heard diabetes before and I didn't know you could prevent it. I heard that like if your parents is diabetic, you get it too. But I didn't know there was prevention to that.

As the above quotation reflects, the community member's knowledge of diabetes was mediated through her experiences with her mother's illness. She came to associate diabetes with dialysis, amputations, and inevitability. During the interviews and focus group, participants were asked to describe their thoughts when they heard the word "diabetes." Responses reflected a wide knowledge. Many described their personal experiences with diabetes and caring for family members with diabetes, and a recurring theme suggested diabetes was inevitable and that those with diabetic family members were "doomed" to develop the disease. One participant diagnosed with diabetes described the onset of the illness in the following way:

All I know is it's inherent, it's by genetics, and there's no way I'm going to get out of it. My mom had it, my dad had it, my grandmother and grandfather had it, there's no way I'm going to get out of it. People looked at me and said "Your dad had it too, eh? You're ... destined, doomed."

Similarly, during a focus group, a participant discussed his certainty of developing diabetes: "Pretty sure I'm going to get it one day, it's coming to me, yes. Yep, all my family has it, it's coming to me now."

For community members, their experiences with diabetes have taught them that it is not preventable. In addition to this sense of inevitability and "doom," fear was commonly associated with diabetes. In particular, many participants discussed the complications of diabetes and their fear of amputations and death. An elementary school teacher described it in the following way:

When I hear about diabetes, I'm afraid of it. Right away I wanna change how we eat because I've seen

a lot of my aunts and uncles losing their legs and they all passed away two years after when they have it.

For another participant, it was emotionally painful to discuss his experiences with his family members diagnosed with diabetes and the complications they developed, which included an amputation. He expressed grief and concern about his partner being recently diagnosed. He was clearly very knowledgeable of the complications and when the focus group facilitator observed this, he responded "My whole family's got it!"

Many participants spoke about the link between diabetes, diet, and manner of living. As one participant diagnosed with diabetes described,

Have to watch your sugar, control what you eat, change your lifestyle ... try to be more active, change your eating habits, like portion size, watch a lot of things that they're selling at the store, junk food.

Another community member, when discussing her fear, explained "I don't want no diabetes, I changed my way of living, my eating habits." Many participants expressed a desire to learn more about how to cook healthy foods to prevent the disease.

In the participant testimonies, an association was clearly present between diabetes and loss, whether it be the loss of a loved one, a body part, or of a manner of living. One participant diagnosed with diabetes described the loss of eating foods she loved, and the changes that are required of her and her family's dietary and exercise habits. The diagnosis was described as a "life-changing event." Another participant who described himself as a hunter and provider discussed the changes in his life and the loss he experienced when diagnosed. No longer able to go for long walks in the bush without a companion, he stated that diabetes "hinders a Native lifestyle." He reported that this affected his relationship with the land, a significant loss for an individual whose identity is so closely linked with this connection. Furthermore, by interrupting his ability to participate in traditional activities and a traditional manner of living, his ability to achieve *minimadizuin* was hindered significantly.

Theme #3: Community members are eager to learn about diabetes and health-promoting strategies

In the planning of our focus groups in Phase One, a miscommunication occurred regarding the purpose of focus group #1. Participants arrived, expecting more of a diabetes information session than a focus group conversation. While the miscommunication was quickly rectified, this glitch was actually fortuitous as it revealed a rather interesting phenomenon. Participants were eager to learn about diabetes, and came prepared with many questions, especially related to their personal concerns. For example, a participant with a young grandson whose weight was being monitored at the clinic asked if children and babies can be born with diabetes. Another participant who discussed her own fears, asked what the first symptoms of diabetes are. Examples of other questions posed included: "Does it cause heart problems? What about anxiety attacks?"; "Is [blurry vision] the first sign?"; "What about cholesterol problems?"

While the student researcher addressed as many questions as possible, she reflected to the participants that they seemed to have many questions about diabetes and asked if they were interested in receiving more information, to which they responded eagerly. This eagerness was also observed during focus group #2, when participants expressed interest in learning about prevention and management strategies.

The community members' eagerness to learn about diabetes was an unexpected finding, considering the multiple educational resources already available at the clinic specific to diabetes. Both the CHR and the diabetes nurse have received extensive training in education on diabetes prevention and management. This unexpected finding was explored with the diabetes nurse who explained that while there may be an interest in learning about diabetes, community members do not currently view the clinic as an educational resource. Rather, community members see the clinic as a place solely to receive treatment or care for a health concern.

COMMUNITY OUTCOMES

DIABETES BINGO!

Following from these thematic findings, we designed an intervention to address the educational

needs of the community. Through online research on various health promotion educational games, the student researcher, diabetes nurse, and CHR posited that a culturally and locally adapted version of Bingo might address some of the educational needs of the community in an engaging manner. Together, the CHR and the student researcher developed the Diabetes Bingo game: the CHR determined the content of the Bingo cards and ensured its cultural relevance; the diabetes nurse assessed the accuracy of the content, and the student researcher formatted the individual cards. Each Bingo card addressed the following topics related to diabetes: risk factors, prevention, symptoms and complications, and how to manage diabetes. Each square contained an image to visually represent the information (see Appendix A for a sample Diabetes Bingo! card).

The Diabetes Bingo! Night was piloted on a week night at the Kitiganik Health Clinic and was attended by 17 community members, plus clinic staff. Participants' ages ranged from mid-twenties to early fifties; 3 of the participants were male and 14 were female. The Bingo game was facilitated by the CHR and the student researcher. Prizes included healthy food items, t-shirts and mugs. Participants seemed to enjoy playing and even asked to continue playing. After the game had finished, a skill testing question on the content of the cards was asked and a prize was given to the first individual who could provide the answer. One participant answered the skill testing question while glancing down at the card, thereby using the educational tool.

All participants were asked to provide written feedback on the Diabetes Bingo! game, the majority of which was positive. Examples of what people liked included that "it was informational and the Bingo card was visual," "it was fun," "having fun learning," and it was "informative, educational." Participants provided suggestions on topics for subsequent activities, including: "alternative medicines," "control blood sugar," "lower blood sugar level," "amputations," and "how to exercise properly for diabetic people." One participant suggested a PowerPoint presentation on diabetes. When asked what participants did not like about the activity, the most common feedback was logistical (e.g., that it started late

and there were not enough snacks). Suggestions to improve the activity included “more hands on activities,” “more outreach to other members of community,” and providing pamphlets on diabetes.

Based upon the feedback, Diabetes Bingo! Night is scheduled to be held monthly at the Kitiganik Health Clinic, facilitated by the CHR with support from the clinic staff. At each event the CHR provides a short discussion on one of the topics presented on the Bingo card. Due to the political division, the CHR plans to alternate the location of the Diabetes Bingo! nights to include a wide variety of community members.

WORKSHOP SERIES

To address the many questions and concerns expressed during the focus groups and as part of the feedback from the community presentation, the “Health and Diabetes Workshop Series” was designed by the CHR, diabetes nurse, and student researcher. This series will be hosted by the CHR at the Kitiganik Health Clinic four times per year. The first workshop will focus on complications related to diabetes, as this concern arose multiple times during the project. Topics for subsequent workshops include: the role of food in health, with cooking classes hosted by the CHR and a nutritionist as a guest speaker, and diabetes awareness with a guest speaker to discuss prevention and management strategies. Other suggested topics include the relationship between diabetes and other diseases, traditional medicines, diabetes during pregnancy, and the effects of diabetes on children.

BUILDING CAPACITY

Through the research partnership and the creation of these activities, capacity building occurred with the CHR, the diabetes nurse, and the student researcher. The CHR played a significant role throughout the research project which further developed her skills in creating education tools to use in the community while applying her extensive knowledge of diabetes and health in the local community context. Her involvement and commitment to providing health education to the community will go far in ensuring the sustainability of the activities. Through this process, both the diabetes nurse and student

researcher learned about *minimadizuin* and the important local knowledge of community members. For the diabetes nurse, this is important to incorporate into her nursing care and diabetes program. For the student researcher, *minimadizuin* broadened her understanding of health and will be incorporated into her future nursing care and work with Aboriginal communities.

DISCUSSION

Aboriginal communities across Canada are facing the challenge of diabetes, with increasing rates of type 2 diabetes and a decreasing age of onset. To address this problem, community-based interventions are needed that incorporate local knowledge and integrate Aboriginal conceptualizations of health. Local knowledge of diabetes must be recognized as important for health care professionals' clinical practice and the development of educational interventions (Boston et al., 1997).

Two elements contributed to the successful outcome of our research project. First, through implementing a participatory research framework, the research topic was identified by the staff of the Kitiganik Health Clinic, who have worked closely with the community for a number of years. This contributed both to the success and the sustainability of the project. Second, the use of multiple data collection methods allowed the student researcher to gain a comprehensive understanding of the community's experiences of health, diabetes and the community's needs.

As part of implementing a participatory approach, the importance of the community members' knowledge and experience regarding health and diabetes was recognized. Similarly, in a research project initiated by the Cree Board of Health and Social Services of James Bay, Boston and colleagues (1997) implemented a participatory framework to address the rising incidence of type 2 diabetes in that community. As the first step to address this health issue, the researchers explored Cree understandings and experiences of type 2 diabetes from which they concluded:

the Cree understanding of health and illness can form the basis of practical information to use

in the construction of policy and programs concerned with diabetes prevention. (p. 11)

As our goal was to develop a health promotion intervention, we felt it imperative to explore the meaning of health and diabetes and to avoid a narrowed focus on illness and disease. Employing this approach, the Algonquin conceptualization of health, *minimadizuin*, was further explored. *Minimadizuin* reflects the Algonquin's health world view (Turton 1997). *Minimadizuin* is achieved through the promotion and balance of the four interrelated aspects of the self: spiritual, physical, mental, and emotional. A balanced manner of living is necessary to achieve health and a traditional manner of living and participating in traditional activities can promote this balance. Community members have identified the many recent and rapid changes in ways of living as the cause for the many illnesses and diseases that are prevalent in the community. For some individuals these illnesses, such as diabetes, challenge their ability to participate in traditional activities and, consequently, to achieve *minimadizuin*.

This conceptualization of health is consistent with other Aboriginal health research. Adelson (1998), for example, explored the meaning of health with the Whapmagoostui Cree of Northern Québec, for whom health is a culturally constructed concept mediated through multiple social, political, and historical processes. Western interpretations of health are typically oriented to the physical body, whereas a broader conceptualization of health is evidenced in the Cree word *miyupimaatisiun*, translated as “being alive well,” where health is linked to manner of living and the land (Adelson, 1998). As with *miyupimaatisiun*, the Algonquin concept of *minimadizuin* represents a holistic understanding of health involving a balance between the four aspects of the self and is connected to the individual's and family's manner of living, particularly the ability to partake in a traditional manner of living.

In the community of Rapid Lake, previous research projects have explored Algonquin perspectives of other health-related concepts. For example, Kooiman and colleagues (2012) explored youth well-being with a self-respect framework to create a culturally adapted health promotion program for

youth. The researchers explored the conceptualization of self-respect with community members; the closest term to “self-respect” in Algonquin culture is *minododazin*. Although similar to *minimadizuin*, community members confirmed that these are two distinct concepts with many similarities. According to Kooiman and colleagues, *minododazin* refers to “taking care of yourself,” and like *minimadizuin*, *minododazin* extends beyond the individual to include family, community, and the environment. With *minododazin*, respect can range from showing deference to an elder to not using drugs to eating well, reflecting a broad and holistic understanding of respect (Kooiman et al., 2012).

One of our principle themes was that community members have a wealth of local knowledge about diabetes that is mediated by their experiences with the illness. When developing the educational activity, this finding helped us to build on the knowledge that community members already possess. Importantly, this local knowledge often diverges from commonly accepted Western biomedical knowledge. For example, among the medical community, diabetes is understood to be a preventable disease whereas for many people in Rapid Lake, their experiences have shown that if their family members have been diagnosed with diabetes, they are “doomed” to get it. Smith (1999, p. 63) describes the Western colonization of knowledge, explaining that Western knowledge defines itself “as the centre of legitimate knowledge, the arbiter of what counts as knowledge.” Smith (1999) further illustrates how Aboriginal knowledge and ways of knowing are often discounted within academia and research. The many years of experience living with diabetes and the knowledge that these individuals possess cannot be discounted as “misinformation”; further, to refer to Aboriginal peoples' knowledge as “perspectives” or “understanding” inadvertently emphasizes Western knowledge as “true” knowledge. The importance of this local knowledge must be appreciated and, as Boston and colleagues (1997) advocate, incorporated into health promotion interventions to ensure their cultural and contextual relevancy.

Community members' eagerness to learn and participate in educational activities supports find-

ings from previous research. Two previous projects with Rapid Lake youth found that youth participants are interested in learning about health-related topics and that adults are receptive to learning from youth (Kooiman et al., 2012; Sherman et al., 2011). Through their research partnership with the Sandy Lake Health and Diabetes Project, Ho and colleagues (2006) also found participants had placed importance on education. Examples include a school prevention program to educate children with participants posing many questions about diabetes and healthy eating (Ho et al., 2006).

Participatory forms of research have been hailed "as a means to promote social justice and equity in health" (Potvin et al., 2003, p. 1295). A growing body of researchers have emphasized the importance of employing participatory research in the public and community health sector, particularly when Aboriginal health is the focus (Boston et al., 1997; Potvin et al., 2003). Potvin and colleagues (2003) highlight the merits of a shift from "a top-down, expert-driven approach" in community health research and program development, to a more egalitarian approach including community participation. This approach involves a shift from the notion of "fixed" programs that are tested outside the local context and inserted into a community, to one that views program development as an interactive and collaborative process between researcher and community (Potvin et al., 2003). Various researchers have demonstrated the use of participatory research in program development within Aboriginal communities significantly contributes to their effective implementation and sustainability, elements key to the ultimate goal of promoting healthy outcomes (Boston et al., 1997; Macaulay et al., 2003; Potvin et al., 2003).

The three key elements of participatory research implemented throughout this project that facilitated its success as a sustainable intervention were collaboration, mutual education, and action. This approach encouraged the active participation of community members in the project by gathering community members' input and feedback. The CHR actively engaged in the project, creating a collaborative and interactive process for developing the health promotion intervention.

Education in participatory research involves a mutual sharing of knowledge among the research partners (Macaulay et al., 1999). One of our objectives was to learn about Algonquin understandings of health and diabetes to create a culturally adapted program. The program was developed by the CHR and student researcher from a respectful sharing of ideas and knowledge. As Daniel and colleagues (1999) describe, successful diabetes education initiatives for Aboriginal peoples must have sociocultural relevancy and cannot be removed from their cultural context. To create and implement an effective educational intervention, they recommend the active participation of community members in the development of these programs. The student researcher presented the goals, knowledge gained, and outcomes of the research project to the community, the presentation serving as an opportunity to share knowledge with the community and to continue learning from community members.

The final key element of participatory research is action. Action, according to this framework, must be based upon the findings of the collaborative research partnership (Macaulay et al., 1999). In this research project, action was achieved through the creation of a sustainable health promotion program that was culturally adapted to address community needs regarding type 2 diabetes.

Spending three months with the community in Rapid Lake gave the student researcher a rich exposure to diabetes and multiple opportunities to engage with the community. As with any research project, we had important limitations around which we worked as best we could. For example, to address our limited time frame, the student researcher participated in nursing activities at the clinic as well as other community activities held at the clinic and the elementary school. This participation allowed her many opportunities to identify and interact with key informants and community members. Another limitation was that the student fulfilled both roles of researcher and research tool which, although fundamental to ethnographic research, increases the risk of personal bias (Polit and Beck, 2008). To address this issue, the student researcher maintained reflexivity through the use of personal field notes

and regular contact with the McGill supervisors and an on-site supervisor, to discuss any methodological or ethical issues that arose.

Another limitation is the ongoing political division in the community. Most of the participants in the project were identified through the Kitiganik Health Clinic; however, some members do not attend this clinic because it is federally sponsored. To address this issue, the student researcher recruited focus group participants through other venues, such as the elementary school. A final limitation is that unfortunately no Elders in the community were successfully recruited to the study.

KNOWLEDGE TRANSLATION AND IMPLICATIONS

As mutual education is one the key tenets of participatory research, knowledge translation and sharing occurred at multiple levels throughout the research. The student researcher worked in partnership with the CHR to develop the Diabetes Bingo! game, through which each learned how to develop and adapt an educational tool to the local context. Further, the Diabetes Bingo! game provided participants with important knowledge on diabetes and has been left with the CHR for future use. The findings and outcomes of the study were shared with the community through a presentation held at the Kitiganik Health Clinic and later shared with the McGill School of Nursing. The community members appreciated the findings of the research project and provided many ideas for the workshop series, including a focus on traditional medicines, support for family members of individuals with diabetes, and educational activities for young women and mothers.

The research project provides an example for health care professionals and researchers to incorporate participatory research principles into the development of culturally and locally adapted health promoting interventions in an Aboriginal community. For the health care staff of the Kitiganik Health Clinic, the research project has provided them with an opportunity to learn about the extensive local knowledge of diabetes held by community members and incorporate it into their practice.

CONCLUSION

Type 2 diabetes has reached almost epidemic proportions amongst Aboriginal peoples in Canada, and is a significant health concern due to the decreasing age of onset and increased risk for future generations. To address this potential "epidemic," health promotion interventions must be culturally adapted and tailored to the local needs and context of each Aboriginal community. Although this research project was conducted in a short time frame, and with a limited focus of inquiry, it provides an example for future research endeavours of implementing the guiding principles of participatory research: collaboration, mutual education, and action. Following these three principles facilitates research projects' ability to create locally and culturally adapted interventions that value the vast knowledge and experience of the community. Employing this approach, the Rapid Lake community members' experiences and knowledge of diabetes were prioritized, not discounted as "misinformation" as may occur in academic literature. By incorporating this local knowledge of diabetes into the educational interventions and sharing this knowledge with the Kitiganik Health Clinic staff, the community members of Rapid Lake are now better equipped to address the "diabetes epidemic."

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Appendix A- Sample Diabetes Bingo! Card

Diabetes Bingo!

Risk Factors for Diabetes	How to Prevent Diabetes	Symptoms Of Diabetes	Complications Of Diabetes	How to Manage Diabetes
Diabetes in Family 	Traditional Foods 	Frequent Urination 	Vision Problems 	Take Medications Regularly 
Overweight 	Exercise 	Fatigue 	Kidney Disease 	Eat Balanced Meals 
Age 40 & Older 	Regular Check-Ups 	Free Space!!	Amputations 	Manage Stress 
High Blood Pressure 	Eat Less Junk Food 	Tingling or Numbness in Feet/Hands 	Stroke 	Check Blood Sugar Regularly 
Diabetes in Pregnancy 	Watch Less TV 	Weight Change 	Heart Disease 	Be Physically Active 