

## **La littérature traitant du diabète chez les Autochtones canadiens : une étude des méthodologies holistiques**

**Sylvia S. Barton**

La promotion de soins adaptés à la culture des personnes atteintes de diabète est une démarche essentielle dans le cadre des efforts visant à s'attaquer aux iniquités infligées aux Autochtones en matière de santé. S'appuyant sur les études publiées de 1995 à 2007, l'auteure présente une analyse descriptive des connaissances portant sur le diabète chez les Autochtones comme outil guidant l'intégration des pratiques infirmières de fine pointe dans les programmes de soins. La recension de la littérature n'est pas systématique mais elle est suffisamment exhaustive pour constituer un cadre théorique pouvant être appliqué dans les programmes de pratiques et de recherche en matière de diabète chez la population autochtone. Concernant les écrits sur un volet particulier de ce sujet, cette recension offre un instantané de la recherche communautaire portant sur cette maladie et axée sur les méthodologies holistiques historiquement utilisées en contexte canadien. La littérature traitant du diabète chez les Autochtones s'est révélée une riche source d'information. Toutefois, l'analyse des méthodologies holistiques indique une insuffisance pour ce qui est de la recherche sur le sujet et une utilisation limitée des principes directeurs holistiques clés quant à la recherche prévisionnelle politique sur les Autochtones.

**Mots clés :** diabète chez les Autochtones, recension de la littérature, soins adaptés à la culture, recherche communautaire portant sur le diabète, méthodologies holistiques, recherche prévisionnelle politique sur les Autochtones

# **Discovering the Literature on Aboriginal Diabetes in Canada: A Focus on Holistic Methodologies**

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Promoting culturally competent care for diabetes is critical to addressing the health inequities of indigenous peoples. Based on a review of studies published between 1995 and 2007, the author presents a descriptive analysis of Aboriginal diabetes knowledge guiding the involvement of advanced practice nurses in programs of care. While the literature review is not systematic, it is sufficiently comprehensive to provide a theoretical backdrop to Aboriginal diabetes programs of practice and research. In terms of a particular area of Aboriginal diabetes literature, it also provides a snapshot of community-based diabetes research focused on holistic methodologies historically used in the Canadian context. The Aboriginal diabetes literature is found to be a source of rich information. Analysis of holistic methodologies, however, reveals underdevelopment of research and limited use of key holistic guidelines for Aboriginal policy research.

**Keywords:** Aboriginal diabetes, literature review, culturally competent care, community-based diabetes research, holistic methodologies, holistic framework guidelines, Aboriginal policy research

Promoting culturally competent care associated with diabetes is increasingly viewed as an important nursing role (Canadian Nurses Association [CNA], 2004) that requires a focus on geographical, linguistic, educational, and social differences among Aboriginal populations and communities. The CNA (2004) views culturally competent care as the application of knowledge, skills, attitudes, and personal attributes required by nurses to provide appropriate care and services in relation to the cultural characteristics of their clients; it includes the valuing of diversity, knowledge about the cultural mores and traditions of the Aboriginal populations being served, and sensitivity in caring for an Aboriginal person.

One leading cause of morbidity and mortality in Native populations in North America is non-insulin dependent diabetes mellitus (NIDDM) (Benyshek, Martin, & Johnson, 2001). The Pima Indians of Arizona are considered to have the highest rate of NIDDM in the world (Farook, Hanson, Wolford, Bogardus, & Prochazka, 2002; Lindsay et al., 2002). The prevalence rates for diabetes in Canada's First Nations are now among the highest in the world (Health Canada, 2000; Young, Reading, Elias, & O'Neil, 2000). Among indigenous peoples of the Americas, South

Pacific, New Zealand, and Australia, diabetes is emerging as an increasing health concern (Anderson, 2000). Nurses have been challenged not only to improve the quality of care for Aboriginal people but also to advocate for best practices in developing strong Aboriginal communities.

Nursing initiatives to address diabetes issues among Canadian Aboriginal peoples are influenced by trends in research and social health policy and by evolving perspectives on Aboriginal health. Globally, there is research consensus that diabetes was close to non-existent in indigenous populations prior to 1940 (Hernandez, Antone, & Cornelius, 1999). Following the Second World War, the prevalence increased dramatically, and diabetes is now considered an epidemic in progress (Young et al., 2000). Researchers in the United States have collected much of the data, while researchers in Canada began to publish 20 years ago when rates among First Nations became noticeable. It has been observed that significant variability in tribal and regional prevalence is indicative of several trends, which are understood to be influenced by profound social, environmental, and lifestyle changes in the past 50 years, leading to the notion of diabetes as an illness of acculturation (Hegele, 2001; Waldrum, Herring, & Young, 2006).

As a result, the understanding of diabetes as a disease varies according to local culture and linguistic group, geographic placement, and degree of isolation. It is a perspective that values the participation of key Aboriginal people and organizations in the promotion of culturally competent diabetes care. Further, it is being shaped by recently established granting agencies, so that an Aboriginal diabetes research agenda will benefit Aboriginal peoples and communities across Canada (Wilson, 2003).

There has been a research shift away from viewing Aboriginal peoples as intriguing or pertinent research subjects and towards viewing them as research partners. A cultural approach to health places an emphasis on conducting research within Aboriginal knowledge traditions using Aboriginal methodologies as well as methodologies drawn from non-Aboriginal intellectual traditions (Smith, 1999). The object is to establish an equal-partner approach to health. In addition, concern with promoting culturally competent care rooted in social and political structures is based on critical social theory, which is directed at addressing oppressive sociopolitical conditions that limit the health potential of all people (Mill, Allen, & Morrow, 2001). The inclusion of different Aboriginal cultural structures in such conditions adds to the complexity.

A holistic framework for Aboriginal research policy would include the following guidelines:

...honoring past, present and future in interpretive and analytical research processes including historical references and intergenerational discourse; honoring the interconnectedness of all of life and the multi-dimensional aspects of life on the Earth and in the community in research design and implementation; and honoring the spiritual, physical, emotional and mental aspects of the person and the community in research protocols, methodologies and analyses. (Kenny, Faries, Fiske, & Voyageur, 2004, p. 8)

These guidelines offer a means to improve research practices or cultural competency, particularly for non-indigenous researchers. They also have implications for the design and conduct of studies, many of which lack access to community membership and to experts in traditional knowledge.

This study had two objectives. The first was to examine the literature on Aboriginal diabetes in the Canadian context between 1995 and 2007 and provide a descriptive analysis of Aboriginal diabetes knowledge guiding the involvement of advanced practice nurses in programs of care. While the literature review is not systematic, it is sufficiently comprehensive to provide a theoretical backdrop to Aboriginal diabetes programs of practice and research. The second was to provide a snapshot of community-based diabetes research on holistic methodologies historically in place in the Canadian context, and to identify the use of key holistic guidelines for Aboriginal policy research. It was hoped that this would reveal holistic research practices that could be applied in future work and would result in suggestions for improvements in this area.

### **Method**

During the initial phase of the review, I examined approximately 130 research articles published in peer-reviewed journals between 1995 and 2007 and addressing diabetes in Canadian Aboriginal populations. I used the CINAHL, MEDLINE, and Alternative Health Watch databases and conducted a manual search of key journals for the years 1995 to 2007, including *Social Science and Medicine*, *Culture, Medicine and Psychiatry*, and *Chronic Diseases in Canada*. I examined reference lists for additional empirical articles and book chapters related to diabetes and Aboriginal peoples. To ensure credibility of the articles retrieved, I included only those studies that employed research designs that described the research approach used.

Later in the inquiry, I selected for analytical review those articles that reported on a community-based empirical study using a Canadian sample, included a declaration by participants of Aboriginal ancestry, and addressed knowledge of diabetes from a cultural perspective. In order for

the diabetes knowledge to be considered cultural, it had to be focused on understanding, preventing, or managing diabetes from an Aboriginal perspective or on evaluating intervention programs. Only English-language publications were selected. Excluded were studies whose primary focus was an epidemiological, cultural, or biological understanding of diabetes or the risk factors and determinants of diabetes. Excluded also were government documents not accessible via an electronic database and studies that consisted of descriptions of programs for Aboriginal people, without a research component.

A total of 26 articles met these criteria. The purpose was to identify the implications of culture-specific knowledge for community-based research programs targeting Aboriginal diabetes and for advanced nursing practice generally. This approach was thought useful for identifying holistic research methods grounded in Aboriginal world views and experience or health policy implications from indigenous perspectives, as well as areas that filled an evident gap. Considering the varied foci of the studies, no attempt was made to present an integrated summary of the findings.

There is a vast literature devoted to diabetes and Canadian Aboriginal peoples crossing disciplinary boundaries — for example, within the biomedical, nursing, and health sciences in the last decade. One must therefore consider the nomenclature used to identify Aboriginal ancestry. In this article I use the terms *Aboriginal* and *non-Aboriginal* provisionally, in the knowledge that these do not accurately reflect differences among people and communities. In the context of Aboriginal diabetes research in Canada, the term *Aboriginal* is used to describe the indigenous inhabitants of Canada, which include First Nations (Status Indian and non-Status Indian), Métis, and Inuit persons. The nomenclature does not reflect the complexity of jurisdictional issues. This is an important issue, because the designations Metis, Status Indian, and Inuit have legal and constitutional implications. First Nations peoples are represented in all 26 articles selected. There is no one *Aboriginal* identity, just as there is no one *non-Aboriginal* identity.

## Findings

### *Synthesis of Aboriginal Diabetes Knowledge*

Research has shown that, among Aboriginal people, the incidence of type 1 diabetes is extremely rare but type 2 diabetes is increasing at an unprecedented rate (Health Canada, 2000). There is great cause for concern about the escalating rate of type 2 diabetes. Compared to the general population, Canada's Aboriginal peoples have earlier onset, higher rates of complications, greater severity of the disease at the time of diagnosis, and greater propensity to harbour risk factors for long-term illness

(Health Canada, 2000; Young et al., 2000). Increasing awareness of the high rates of diabetes among the Aboriginal population has led scholars to articulate a health promotion and illness prevention mandate. This is seen as a way to challenge environmental, social, and lifestyle factors that influence diabetes health, including increased fat intake, reduced physical activity, and an inherited susceptible genotype (Hegele et al., 1999; Lieberman, 2003; Schultz, 1999). The CNA's (2002) position statement on advanced nursing practice describes the leadership role as one of promoting high-quality care by guiding the activities of a person or group. It is by offering guidance and developing innovative approaches to clinical practice that nursing will advance as a discipline. Changing conceptualizations of research and research approaches, as well as rising diabetes rates (Health Canada, 2000), have contributed to the renewed interest among policy-makers and health professionals in promoting culturally competent care for Aboriginal persons with diabetes.

Diabetes is a long-term condition that can lead to medical complications and disability, including kidney disease, heart and circulatory disease, blindness, amputations, nervous disorders, birth defects, and premature death (Valer, 2000). In Canada, prevalence rates are lowest in the Northwest Territories and Yukon Territory and highest in the province of Ontario (Maberley, King, & Cruess, 2000). The prevalence of type 2 diabetes is known to vary substantially within and among Aboriginal groups, as well as in geographic distribution across the country (Bruce, Kliever, Young, Mayer, & Wajda, 2003; Delisle & Ekoe, 1993; Green, Blanchard, Young, & Griffith, 2003; Piore, Dyck, & Gillis, 1996). Although previously geography was considered a predictive factor in type 2 diabetes among Aboriginal people (Young, Szathmary, Evers, & Wheatley, 1990), caution should be exercised regarding the tendency towards geographic determinism. Several claims have been made about a pattern in the incidence of diabetes, such as that the frequency of type 2 diabetes decreases as latitude increases and that there exists a west-east prevalence gradient. Moreover, diabetes rates among Aboriginals are known to be higher on-reserve than off-reserve (Health Canada, 2000). However, complex historical and political factors must also be taken into account. For example, few reserves were established in the Northwest Territories or Nunavut, and the latest Statistics Canada (2008) data show that more First Nations people live off-reserve than on-reserve.

Compared to non-Aboriginal Canadians with diabetes, Aboriginals are more susceptible to developing complications and have higher diabetes-related mortality rates (Hanley et al., 2005). Macaulay et al. (2003) found that among Aboriginals with diabetes in Kahnawake, Quebec, 25% had retinopathy after 10 years of long-term illness. This compares to just over 10% of the general population with diabetes, according to the

National Institutes of Health in the United States (Macaulay et al., 2003). In a recent study, Hanley et al. (2005) found evidence of early neuropathy in 46.3% of Aboriginal people in Sandy Lake, Manitoba. Data on lower-limb amputations among Canadian Aboriginal people cited in a Manitoba study show that 91% of all lower-limb amputations among First Nations people involved patients with diabetes (Health Canada, 2000). Green et al. (2003) suggest that, among people with diabetes, Aboriginals are more likely than non-Aboriginals to develop nephropathy and end-stage renal disease (ESRD), and that, among those who do develop ESRD, Aboriginals are more likely than non-Aboriginals to require dialysis. Health Canada (2000) reports that “in Manitoba, it is estimated that an Aboriginal person is 12 times more likely to have diabetic nephropathy than a non-Aboriginal person...and that 71% of new persons (First Nations) on dialysis are adults with diabetes” (p. 17). In terms of heart disease and stroke, Macaulay et al. (2003) found that, among a Mohawk tribe in Quebec, half the participants with diabetes presented with significant heart disease that had led to heart attack and coronary bypass surgery (Health Canada, 2000). Montour, Macaulay, and Adelson (1989) found that rates of macrovascular disease among male and female diabetic participants were higher among the Mohawks of Kahnawake than among Cree/Ojibwa tribes in Ontario and Manitoba.

Given the link between maternal diabetes and the development of NIDDM in children, the high risk of perpetuating a cycle of diabetes has cultural implications for nursing practice, education, and research (Dabelea, Knowler, & Pettitt, 2000), especially as the birth rate among all Canadian Aboriginals remains high, particularly on reserves. The prevalence of gestational diabetes among James Bay Cree women (in Canada) is twice that among women in the general North American population and the second highest reported in any indigenous population worldwide (Rodrigues, Robinson, & Gray-Donald, 1999). Women who have had gestational diabetes are at high risk for developing NIDDM, and their biological children are at high risk of becoming diabetic (Dyck, Klomp, Tan, Turnell, & Boctor, 2002).

The American Diabetes Association (2002) reports the emergence of a disturbing picture in North America regarding diabetes in children and adolescents. Data from population-based studies with Aboriginal children in Manitoba in 1997 reveal that NIDDM is occurring in these age groups (American Diabetes Association, 2000).

Aboriginal leaders, Aboriginal community elders, and many authors have argued that primary prevention of diabetes for Aboriginal children and youth is the only solution to a foreseen public health disaster as the adverse outcomes associated with diabetes and other cardiovascular risk

factors become evident with the maturation of these populations. (Paradis et al., 2005, p. 333)

Empirical evidence has led to important developments in our understanding of diabetes as an imminent epidemic in North America and a major health concern worldwide. As a result of previous Aboriginal research, cultural transitions from traditional to modern lifestyles associated with environmental changes are implicated, along with a genetic susceptibility, in the development of NIDDM in indigenous populations (Gittelsohn et al., 1998). Obesity, fasting blood glucose, and insulin concentrations are all risk factors for diabetes. Studies investigating the mechanism through which exercise might prevent NIDDM have begun to focus on indigenous populations, many of whom have developed a demonstrably greater resistance to insulin. Lack of exercise continues to be a significant risk factor for NIDDM (Kriska et al., 2001). It is postulated that hyperinsulinemia, insulin resistance, and ultimately glucose intolerance, particularly in those who are obese, result from a sedentary lifestyle (Stoddart, Blevins, Lee, Wang, & Blaackett, 2002). These findings are important for several reasons. First, diabetes is complex and the variation in rates among different indigenous groups requires more research. Second, as research continues to identify the epidemiological features of diabetes, there are concerns that diabetes programs are not benefiting indigenous people. Third, much of the empirical evidence is replete with examples of the limited effectiveness of particular diabetes approaches adapted to meet the needs of different indigenous groups in North America (Boston et al., 1997).

In response to these issues, there have been calls by health professionals worldwide for effective community-based screening and primary prevention programs (Griffin, Gilliland, Perez, Upson, & Carter, 2000; Meltzer et al., 1998). Research has shown that pre-diabetes conditions are reversible through lifestyle interventions such as dietary improvements and increased physical activity (Diabetes Prevention Program Research Group, 2002; Uusitupa et al., 2000). Community-based diabetes prevention initiatives can form a basis for comparing the health of Aboriginal people with diabetes in Canada to that of indigenous people with diabetes in other countries. Such comparative information could serve to enhance our understanding of how social, political, and cultural contexts influence Aboriginal healing and well-being.

### ***Focus on Holistic Methodologies***

This analysis of 26 community-based Aboriginal diabetes studies provided an opportunity to identify the positive outcomes associated with innovative research approaches that attempt to balance scientific exper-



tise with indigenous perspectives, values, and community priorities. Of the 26 studies, 11 examined the effectiveness of an intervention program and explored Aboriginal approaches to learning as a result of screening initiatives to evaluate community-based diabetes programs. Two studies focused on understanding factors associated with Aboriginal perspectives, one addressing the Aboriginal meaning of diabetes and the other the sociocultural origins of diabetes. Eight articles report on a community-based participatory research project, the Kahnawake Schools Diabetes Prevention Project of the Centre for Research and Training in Diabetes Prevention.

### Discussion

The 26 studies analyzed were innovative and were well received and supported by the communities. The majority of designs isolated, to varying degrees, holistic elements that could be described as contributing to the success of a program. The criteria for determining the degree to which the design played a role in this success were drawn from the teachings and values of Aboriginal cultures — respect, relevance, reciprocity, and responsibility. The relationship that the researchers developed with Aboriginal community members had to be centred on *respect* for who they were, to be *relevant* to their world view, to be *reciprocal*, and to enhance their ability to take *responsibility* for their own lives. This amounts to no more than a snapshot of community-based diabetes research focused on holistic methods employed in the Canadian context. It points to the need for more research of this kind and the need for researchers to articulate how qualitative methodologies, in particular, can isolate the holistic elements of a program's success and the implications for Aboriginal health policy.

These studies represent an attempt to move away from colonial research approaches — which tend to be secular, fragmented, and objective — with the aim of discovering not definitive truths but, rather, multiple realities. New frameworks serve to deepen our understanding of events, which points to the need for exploration beyond the colonial paradigm. All paradigms have their limitations, however, and any attempt to replace colonial frameworks with holistic ones in pursuit of definitive truths should be viewed with caution. There simply are no definitive truths, and models claiming that there are should also be approached with caution. This applies particularly to the complex history of Aboriginal and non-Aboriginal relationships. Ermine (1995) explains that “those who seek to understand the reality of existence and harmony with the environment by turning inward have a different, incorporeal knowledge paradigm that might be termed [indigenous spiritualism]”

Table 1 *Studies of Community-Based Aboriginal Diabetes Using Holistic Methodologies*

<p><b>Author(s) Study Participants Province</b></p>	<p><b>Research Strategy and Key Findings</b></p>	<p><b>Inclusion of Aboriginal Perspectives in Design and Conduct</b></p>	<p><b>Use of Key Holistic Guidelines for Aboriginal Policy Research</b></p>
<p><b>Daniel &amp; Green (1995)</b> Three Okanagan First Nations communities British Columbia</p>	<p>Population approach to undertaking a high-risk screening initiative in three communities. Identification of people with undiagnosed diabetes who provided baseline data for evaluating the effectiveness of an intervention program based on systematic summative evaluation. Baseline data included diagnostic assessments and physiological, anthropometric, psychosocial, and behavioural risk-factor screening activities.</p>	<p>Describes how the goals and objectives of a community health promotion program are used in an intervention in Aboriginal communities.</p>	<p>Evidence of interventions that nurture holistic health or balance as opposed to taking a problem-based approach to prevention.</p>
<p><b>Garro (1995)</b> Anishinaabe Manitoba</p>	<p>Interviewing of persons diagnosed with diabetes. The research methods, which centred on oral discourse, revealed the ways in which people account for their own diabetes, the increased incidence of diabetes, and how diabetes is a result of poor dietary choices as well as environmental and social change.</p>	<p>Reduces the conceptual gap between Anishinaabe perceptions of health and more universally accepted Western ones.</p>	<p>Evidence of assessing the relationship of perceived holistic health with self-reported management of diabetes.</p>

<p><b>Travers (1995)</b> Cape Breton Mi'kmaq Nova Scotia</p>	<p>Qualitative and participatory research strategies. An understanding of the sociocultural origins of diabetes related to policy, the market economy, and health care.</p>	<p>Studies diabetes in its natural context in order to preserve the perspectives of the Mi'kmaq people, retain the holistic nature of diabetes, and value participation of the Mi'kmaq people.</p>	<p>Better social/cultural understanding led to culturally relevant policies and practices for preventing and managing diabetes in Aboriginal communities.</p>
<p><b>Robinson et al. (1995)</b> James Bay Cree Ontario</p>	<p>Prospective cohort study to assess weight, blood sugar, and activity level in diabetics after a 3-month return to hunting and trapping lifestyle. Bush living increased physical activity but not enough to adequately control diabetes.</p>	<p>No evidence of Aboriginal perspectives in the design or conduct of the study.</p>	<p>No evidence of culturally relevant understanding of dietary and physical activity patterns among the James Bay Cree.</p>
<p><b>Hanley et al. (1995)</b> Remote northwestern First Nations community Ontario</p>	<p>Describe background, methods, and lessons learned in developing and implementing a prevalence screening and risk-factor survey.</p>	<p>Evidence of an amicable relationship with the community, a high participation rate, and high quality and broad scope of information collected, which was seen as making the Sandy Lake Health and Diabetes Project successful.</p>	<p>Excellent participation and community response attributed to the partnership established between the researchers and the community and to the employment of local people as recruiters and interviewers.</p>

<p><b>King-Hooper, Schulz, &amp; Watts (1995)</b> Nuu-chah-nulth British Columbia</p>	<p>Describe the Nuu-chah-nulth experience of participating in a community-based diabetes education program. Quantitative and qualitative information was combined to develop culturally appropriate, community-based prevention strategies. Many valuable lessons learned during the process, framed around an established partnership with the community.</p>	<p>Seeks the perspectives of Aboriginal community members as they participate in a community-based program, aiding the empowerment of individuals and groups.</p>	<p>Use of acceptable, meaningful, and relevant strategies, resulting in positive outcomes.</p>
<p><b>Dyck &amp; Cassidy (1995)</b> First Nations Saskatchewan</p>	<p>Link physical activity and reduced incidence of gestational diabetes. Strategies for including community members in the inception, development, and implementation phases.</p>	<p>Introduces strategies that are acceptable and meaningful to the participants.</p>	<p>Acknowledgement that a better understanding of Aboriginal culture, traditions, and ways of learning is necessary to bring about positive quantifiable outcomes related to behavioural change.</p>
<p><b>Morrison &amp; Dooley (1996)</b> Sioux Ontario</p>	<p>Describe role of Sioux Lookout Diabetes Program in preventing and managing diabetes. Identification of Aboriginal approaches to addressing diabetes and guiding community-based, culturally sensitive interventions.</p>	<p>Achieves positive changes relevant to community-based interventions by monitoring change over time.</p>	<p>Evidence of having used methods to build rapport with community members and to obtain feedback about specific interventions on a continuing basis.</p>

<p><b>McComber et al. (1996)</b> Mohawk Ontario</p>	<p>Description of how Kahnawake Schools Diabetes Prevention Project (KSDPP) used community participation as a way of preventing diabetes in future generations through diet and exercise.</p>	<p>Understands that, for many Mohawk people, diabetes health is more about well-being than about the absence of physical ailments.</p>	<p>Evidence of having considered the meaning of the self in relation to physical ailments and connections to other aspects of the self.</p>
<p><b>Herbert (1996)</b> Haida British Columbia</p>	<p>Describe how Haida Gwaii Diabetes Project contributed to the empowerment of the community. Sheds light on historical background of local identity and how partnerships support the principles of participatory research.</p>	<p>Evidence of a shift towards viewing community members as key experts.</p>	<p>Evidence of incorporating the voice of the community, which encourages respect for culture and integration of local knowledge systems.</p>
<p><b>Gittelsohn et al. (1996)</b> Ojibwa Cree Ontario</p>	<p>Describe use of culturally appropriate, community-based diabetes prevention strategies. Model developed for use in evaluation research proved useful in diabetes interventions.</p>	<p>Evidence that a community-based approach to diabetes prevention was implemented.</p>	<p>Evidence of understanding that knowledge is useful only if it benefits the community.</p>
<p><b>Boston et al. (1997)</b> James Bay Cree Ontario</p>	<p>Address the meaning of diabetes and use participatory action research to reveal the meanings ascribed by a group of Aboriginal people to the rising incidence of diabetes. Collaborative inquiry found that the James Bay Cree attribute diabetes to colonial influences and to the decrease in bush living.</p>	<p>Cree knowledge and experience of diabetes are viewed as fundamental to any intervention for prevention.</p>	<p>Recruits from the Cree community became co-researchers in the study.</p>

<p><b>Macaulay et al. (1997)</b> Mohawk Ontario</p>	<p>Describe how a variety of intervention models were used to develop the KSDPP, including intervention and evaluation components. Use of qualitative methods to examine the program's life cycle.</p>	<p>Understands that, from a Mohawk perspective, <i>living in balance</i> is being well in mind, body, emotion, and spirit.</p>	<p>The overall goal of the program embodied the concept of <i>living in balance</i>.</p>
<p><b>Daniel et al. (1999)</b> Rural First Nations population British Columbia</p>	<p>Focus on the effectiveness of community-directed diabetes prevention and management, combining qualitative and quantitative information. Community-based actions need to focus on risk conditions (political, economic, and social subjugation) and living standards as well as risk factors (obesity, lack of exercise, poor diet).</p>	<p>Evidence of an attempt to narrow the gap between biomedical knowledge and Western health services, thus increasing the ability to address the diabetic needs of Aboriginal people in culturally specific ways.</p>	<p>Acknowledgement of the need to learn more about Aboriginal ways of being, in terms of oral traditions and ways of building trust, exchanging information, and forming relationships.</p>
<p><b>Jimenez et al. (2003)</b> Mohawk Quebec</p>	<p>Assess diet of Mohawk children in grades 4 through 6 using 24-hour recall after 4 years of participation. Statistical comparisons across assessments found no significant difference in the mean intake of energy, fat, and sucrose; significant decrease in consumption of high-fat foods and fruits; significant increase in energy contribution of white sugar.</p>	<p>The nature of the differences observed reveals the complexity of food choices and the need for interventions that are responsive to changes in the environment, such as in the food supply.</p>	<p>The complexity of food choices calls for interventions that respond to the needs of Mohawk children and their families with practical information.</p>

<p><b>Potvin, Cargo, McComber, Delormier, &amp; Macaulay (2003)</b> Mohawk Quebec</p>	<p>Elaborated four components of an implementation model of community programs: integration of equal partnership; structural and functional integration of the research components; flexibility in response to environmental demands; and a project that represents learning opportunities for all participants.</p>	<p>Evidence that the program is conceived as a dynamic social space defined through an ongoing process of negotiation.</p>	<p>The research and evaluation results revealed a need for all involved to reflect on the program and appropriate the lessons.</p>
<p><b>Cargo et al. (2003)</b> Mohawk Quebec</p>	<p>Examine perceptions of community ownership among project partners who took responsibility for decision-making in the context of the KSDPP.  At 18 months and 60 months, project partners were surveyed cross-sectionally and their perceived influence assessed for three domains related to KSDPP activities and operations and to Community Advisory Board (CAB) activities.  High mean scores for perceived influence for CAB members and community researchers suggested that decision-making was perceived as a responsibility shared among multiple community partners.</p>	<p>Consistent with Kanien'kehaka (Mohawk) culture, participatory democracy, or shared decision-making, is viewed as the primary mode of governance for the KSDPP.</p>	<p>Evidence that the KSDPP is perceived as an empowering and empowered community organization.</p>

<p><b>Delormier et al. (2003)</b> Mohawk Quebec</p>	<p>Develop a theoretical framework of program implementation using a program in its sustainability phase: the KSDPP. This qualitative study retrospectively analyzed diabetes prevention activities implemented over 11 months by the KSDPP intervention staff.</p>	<p>During the entire intervention cycle, the implementation of activities has promoted <i>living in balance</i> and reflected local cultural values.</p>	<p>Teaching, enabling, reinforcing, networking and role modelling strategies were aimed at individual capacity-building and the creation of community spaces for children to have healthy lifestyles.</p>
<p><b>Levesque, Cargo, &amp; Salsberg (2004)</b> Mohawk Quebec</p>	<p>Develop a culturally appropriate interactive computer program for Kanien'kehaka (Mohawk) children to self-report physical activity in groups. A qualitative approach using focus groups eliciting discussion and drawing about physical activity. Compilation of 30 physical activity and 14 non-physical activity choices with accompanying intensity options, which the children could make with assistance.</p>	<p>The development of PAIR is viewed as acceptable to children between 9 and 13, with most requiring no assistance.</p>	<p>An emphasis on flexible programming made PAIR an easily adaptable tool for accommodating diverse Aboriginal populations, different seasons, and changing trends with respect to physical activity.</p>



<p><b>Bisset, Cargo, Delormier, Macaulay, &amp; Potvin (2004)</b> Mohawk Quebec</p>	<p>Describe the conditions in the Kahnawake community that resulted in mobilization for type 2 diabetes prevention.</p> <p>Data collection and analysis were guided by grounded theory, resulting in the description of a phase preceding formal KSDPP implementation.</p>	<p>The phase “legitimizing diabetes as a community health issue” was understood as a shift (from living with a problem to preventing a problem) in the perceived preventability of diabetes.</p>	<p>The shift in perceptions involved understanding the context of an Aboriginal community, including structure and cognitive and relational elements. The use of lay knowledge in planning a health promotion intervention was viewed as critical.</p>
<p><b>Levesque, Guilbault, Delormier, &amp; Potvin (2005)</b> Mohawk Quebec</p>	<p>Use of an ecological lens to deconstruct the programming approach served to unpack physical activity interventions implemented through the KSDPP.</p> <p>Description of physical activity intervention through archive retrieval and interviews with intervention staff.</p> <p>Complex intervention package found to contain a host of multitarget, multisetting intervention strategies designed and implemented through dynamic exchange among diverse community partners.</p>	<p>The study was a first step in understanding community intervention packages and strategies for promoting physical activity in a community setting.</p>	<p>An emphasis on the potential for results to determine which type of intervention strategy is most effective for a given target group in a specific setting.</p>

<p><b>Paradis et al. (2005)</b> Mohawk Quebec</p>	<p>Report on the impact on body size, physical activity, and diet of an 8-year community-based diabetes prevention program for elementary school children in a Kanien'kehaka community. Participants in the intervention and comparison community were followed up (1994–96) and cross-sectional measurements taken in the intervention community (1994–2002) were repeated.</p> <p>Some successes in reducing risk factors for type 2 diabetes were shown in early results, but these benefits did not endure over the 8 years.</p>	<p>This intervention model combined traditional Native learning styles, social learning theory, the Precede-Proceed model, and the <i>Ottawa Charter for Health Promotion</i>.</p>	<p>A focus on participatory research, community ownership, and true grassroots participation throughout planning, delivery, and evaluation. Acknowledgement that policy and environmental changes and community-wide behavioural changes with respect to nutrition and physical activity are hard to achieve in the short term.</p>
<p><b>Cargo et al. (2006)</b> Kahnawake Quebec</p>	<p>To understand the social context of program implementation, a qualitative study was undertaken with the aim of identifying the schoolteacher's role in implementing the objectives of the KSDPP, a locally governed Kanien'kehaka community-based diabetes prevention program.</p>	<p>Health promotion emphasized the importance of community ownership in the governance of community-based programs.</p>	<p>Evidence that participatory democracy or shared decision-making is a strong value.</p>

*(continued next page)*

<p><b>Cargo et al. (2006)</b> Kahnawake Quebec (continued)</p>	<p>Prospective semi-structured interviews were conducted cross-sectionally with 30 teachers over 4 years.</p> <p>In implementing KSDPP objectives, teachers used the health education curriculum to varying degrees in enforcing the school nutrition policy, role modelling, and encouraging a healthy lifestyle.</p> <p>Findings show that children in different classrooms were exposed to a different intervention dose based on the extent to which teachers applied each element.</p>		
<p><b>Cargo, Person, Levesque, &amp; Macaulay (2007)</b> Mohawk Quebec</p>	<p>Assess the relationship of perceived holistic health with self-reported physical activity and television-watching in a sample of Kanien'kehaka youths living in a Mohawk community.</p> <p>Youths who were <i>living in balance</i> tended to be more physically active and to watch less television.</p>	<p>Evidence of the development of a culturally relevant measure of perceived holistic health supported by the Onkwehonwe idea of balance as symbolized in the Medicine Wheel.</p>	<p>Acknowledgement that challenges remain in terms of operationalizing subjective concepts such as holistic health within the Western science model.</p>

<p><b>Pierre, Receveur, Macaulay, &amp; Montour (2007)</b> Mohawk Quebec</p>	<p>Identify barriers to and facilitators of healthy food choices in children aged 6 to 12 in Kahnawake and help orient KSDPP to improve the diet of children.</p> <p>Focus groups (4) were conducted with 15 mothers of children enrolled in one of the two intervention schools.</p> <p>Results showed that cost, time, taste, season of the year, pressure from family and friends, and health concerns within the family can be both barriers to and facilitators of healthy eating for children.</p>	<p>Evidence that the KSDPP was considered a facilitator.</p>	
<p><b>Kirby, Levesque, Wabano, &amp; Robertson-Wilson (2007)</b> James Bay Cree Ontario</p>	<p>Investigate the relationship between perceptions of the environment and physical activity (PA) and walking patterns in Aboriginal adults, in order to inform the planning and implementation of community-relevant PA interventions.</p> <p>A survey of 263 residents of Moose Factory were asked about environmental factors related to walking and PA involvement.</p> <p>Hierarchical multiple regression suggested that a supportive environment is important for PA and that walking and activities of different intensity are mediated by perceived different environmental variables.</p>	<p>Emphasis placed on implications of promoting physical activity in rural environments where Aboriginal people face unique challenges such as bears, mosquitoes, and extreme cold.</p>	<p>Evidence that the relationship between remote rural environments and the involvement of Aboriginal people in physical activity is not understood.</p>

(p. 103). The desire to understand Aboriginal perspectives is not easy to fulfil through research. Couture (1991a) highlights the centrality of spirituality for indigenous peoples by describing “the spiritual as belonging to the world” (p. 60). Thus indigenous perspectives on spirituality demand recognition and respect, if Aboriginal people are to participate in research and if Aboriginal perspectives are to be incorporated into the research process.

These 26 articles also reveal underdevelopment of research and limited use of key holistic guidelines for Aboriginal policy research. And they merely scratch the surface of knowledge that is reflective of Aboriginal ways of interpreting the world while simultaneously being part of or at one with it. In other words, there is much work to be done in conceptualizing indigenous non-dualistic thinking as distinct from colonial dualistic thinking within community-based Aboriginal diabetes research.

Indigenous perspectives, however, are finding their way into colonial systems of research. Further, theoretical exploration of indigenous cultures is enhancing our understanding of contextual orientations, even if we still have a way to go. Although the incorporation of Aboriginal knowledges into health research has the potential to increase cultural relevance, future studies are challenged to, for example, operationalize Aboriginal concepts of holistic health. In navigating the research space between Aboriginal and Western ways of constructing knowledge, studies must be able, from a design perspective, to assess many aspects of Aboriginal understanding of holistic health, healing, and well-being. Efforts to be less reductionistic may be facilitated through incorporation of the community expertise that gives the face and content validity of new measures their meaning and relevance (Cargo et al., 2003). Ermine (1995) describes the contextual orientation of an indigenous spiritual perspective as “the inner space, that universe of being within each person that is synonymous with the soul, the spirit, the self, or the being. [It is that] priceless core [existing] within each of us” (p. 103). Couture describes the cultural orientation of indigenous theoretical exploration:

Traditional [indigenous] holism and personalism as a culturally shaped human process of being/becoming, is rooted in a relationship with Father Sky, the cosmos, and with Mother Earth, the land... This relationship... [is] marked by a trust and a respect which stems from a direct and sustained experience of the oneness of all reality, of the livingness of the land. (1991b, p. 207)

Non-dualistic thinking develops a physical image of the spiritual. The thoughts of the “world” are as creatures, and processes of growth and becoming, and not as abstract concepts and explanations. [Indigenous]

awareness and perception is of the spiritual as belonging to this world, and not to some beyond. (1991a, p. 60)

If indigenous perspectives are to advance our understanding of new orientations of diabetes within empirical research, they will have to be differentiated from the effects of non-indigenous perspectives. Cajete (1994), for example, describes the notion of interconnectedness as socio-cultural in relation to an indigenous perspective. For indigenous people, he states, “this primary context of relationship and meaning is found in the natural environment. In a sense, all traditional [indigenous knowledge] can be called environmental [knowledge] because it touches on the spiritual ecology of a place” (p. 193). Thus, explains Couture (2000), a healing path into what indigenous participants know and want to know is about “uncovering the [indigenous] story” or uncovering “some of the underlying realities and processes that mold the topography of the traditional, [indigenous] mind” (p. 157).

Each indigenous research participant embodies the orientations and perceptions that will influence diabetes experiences and practices. Battiste (1998) states that we need research (and education) that

draws from the ecological context of the people, their social and cultural frames of reference, embodying their philosophical foundations of spiritual interconnected realities, and builds on the enriched experience and gifts of their people and their current needs for [healing and well-being]. (p. 21)

Thus, if our research findings are to be credible and relevant to indigenous peoples, we will have to explore research approaches that are based on forms of shared inquiry that incorporate elements of holistic, interdisciplinary, and community-based design.

The authors of the 26 articles acknowledge that evidence of positive experiences and practices in their findings was supported by an association between diabetes and indigenous perspectives, which provided a starting point for exploring theoretically indigenous culture as different. They also acknowledge the need for their findings to be interpreted in relation to information associated with local customs, perceptions, and definitions of diabetes. In addition, they view culture-specific knowledge as enhancing the utility of local diabetes research conducted by health professionals, especially if guided by Aboriginal people.

Implicit in the studies is an emphasis on the complex interplay of socio-economic and political factors, including broad historical processes and local circumstances, with measurable positive health practices displayed by the recipients of diabetes care programs. Those influences, however, had to be explored theoretically, in order to reveal precisely what culture-specific knowledge was being understood in the discussion.

New approaches to shared inquiry depend on the willingness of researchers to employ research designs that will bring the perspectives and experiences of indigenous peoples into the research process.

McClure, Boulanger, Kaufer, and Forsyth (1992), in an extensive review of current policy issues concerning indigenous populations worldwide, find that indigenous people's new sense of empowerment is contributing to the changes taking place in the areas of health, community development, and community management. Thus shared inquiry based on co-participatory approaches that empower participants to take ownership of the research process have a good chance of generating culture-specific knowledge, as well as providing direction for research with indigenous peoples.

### **Conclusions**

This study found that the literature on Aboriginal diabetes is a valuable source of rich information, but that a range of innovative, community-based research initiatives are needed in Canada and globally. An analysis of 26 select community-based studies of Aboriginal diabetes revealed a number of elements that are important and relevant for those using key holistic guidelines for Aboriginal policy research. It also revealed gaps in culture-specific knowledge. The explicit incorporation of holistic frameworks into ethical research with Aboriginal people will help to inform choices about the design of studies, as well as the processes to be used. An explicit discussion of how guidelines are shaping research practices would be useful in disseminating holistic guidelines for new researchers in the field as well as in demonstrating best practices.

One of the issues to emerge from this focus on holistic methodologies is the need for local customs, perspectives, and beliefs to be incorporated into biological and cultural diabetes research on the healing and health practices of indigenous peoples worldwide. Without such an effort, community-based Aboriginal diabetes research will have little influence on indigenous health. Culturally competent advanced practice nurses are in an excellent position to contribute expertise to the development of holistic frameworks, especially if these frameworks include indigenous perspectives and theoretical explorations of Aboriginal culture and its diversity in the research discussions on diabetes health.

One implication of this new research culture is that the importance and relevance of guidelines for a holistic framework that reflects Aboriginal values and practices must be widely promoted among practitioners and researchers working with Aboriginal communities. To address this challenge, researchers could focus on community-based Aboriginal diabetes initiatives that use mixed-method approaches informed by the

development of a holistic framework for Aboriginal policy research. These approaches could be combined with a broad range of qualitative methods whose design and implementation embody indigenous ways of being, knowing, and doing, which are vital to the exploration of diabetes among Aboriginal peoples.

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### Author's Note

The author acknowledges the financial support of the Social Sciences and Humanities Research Council of Canada (Doctoral Fellowship Award #752-2002-1330), the University of Alberta Faculty of Nursing, and the University of Northern British Columbia.

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