

From Woundedness to Resilience



In 1938, Abraham Maslow conducted research among the Northern Blackfoot in Alberta, near Geichen and Cluny. As a budding psychologist, he was interested in certain cross-cultural issues: wealth, dominance and emotional security. He discovered that the Blackfoot idea of wealth was based not upon accumulation but upon generosity. He also discovered that some of his assumptions—that the drive to obtain power and to dominate were universal—was misguided. In his exploration of emotional security, he found, much to his amazement, that the Blackfoot were so emotionally secure “that about eighty to ninety percent of the population must be rated about as high in ego security as the most secure individuals in our [own] society, who compromise perhaps five to ten percent at most.”¹ In trying to discover why this might be so, Maslow investigated child-rearing practices. He concluded that an emphasis upon personal responsibility was the explanation: parents encouraged their children to do things for themselves and not to expect parents to cater to their every need. As well, the development of close and warm social relationships, particularly as part of large and extended families, led to the creation of very emotionally secure individuals. Maslow’s ideas about human beings and their development were changed as a result of his encounter. He went on to develop the hierarchy of needs, based somewhat upon what he learned from Blackfoot elders.

At the dawn of the 21st century, as we enter a new millennium, five centuries after Columbus, we are learning again the lessons from our cultural teachings and heritage. After a lengthy period of suppression, they are emerging as important understandings about how to live in the world. Many of us carry with us a sense of woundedness, as evidenced by the widespread healing movement that has emerged over the last decade. Coupled with the emergence of the therapeutic state, we are taught that we are somehow wounded and in need of healing. The emergence of a “post-colonial psychology” is contributing to our movement away from a period of great pain.

Part of the healing journey is to begin to see ourselves differently, to move from seeing ourselves as wounded to seeing ourselves as resilient. Resilience is the ability to spring back and successfully adapt to adversity. Seeing ourselves as resilient can be difficult. It is comforting to continue to see ourselves in the old way. There are many structures that help us to do that. Maslow, again, said that, “It would seem that every human being comes at birth into society not as a lump of clay to be molded by society, but rather as a structure which society may warp or suppress or build upon.”²

In a critical analysis of the terms “woundedness” and “resilience,” Lavallee and Clearsky, two Indigenous medical doctors, ask us to look behind these words and ensure that we do not continue the structures that “may warp or suppress” Aboriginal peoples. They remind us to be mindful of the colonial reality; that the use of the term “woundedness” continues the stereotype. They remind us that resilience may be seen as a polite expression of a Darwinian belief about the survival of the fittest.

Ted Reicken reports on the findings of the Traditional Pathways to Health project, a community health project in Victoria. The project used the development of health videos by Aboriginal high school students as the foundation for decolonizing practices that create a sense of agency as well as a sense of connection, not just to one another but to a broader community, culturally, geographically, and across time. Again, we find support for Maslow, and by implication, the Blackfoot notion of community and connection and doing things for oneself.

Yoshitaka Iwasaki and Judith Bartlett find similar results in their analysis of stress-coping among Aboriginal individuals living with diabetes in a Canadian city. Not only did they find that stress was a significant aspect of living with a health problem, they also found that stress originated from larger societal structures and dynamics. Significantly, the participants coped with the stress by drawing upon cultural teachings that emphasized collective strengths, spirituality and cultivation of cultural identity. A view of stress-coping was constructed within a specific cultural context.

Kim A. Critchley et al. and Douglas Durst et al. examine two very different populations. Critchley's study of physical health practices of Mi'kmaq children in Prince Edward Island demonstrates the need for children to be continually engaged in physical activities as a way to build confidence, self-esteem and feelings of success. Durst's study of urban First Nations People with disabilities indicates that those with physical disabilities are often isolated from community life, a life of connection that we have seen as important to developing resiliency.

Bonnie Jeffery et al. report on their work developing health indicators with three northern organizations, the Inuit Tapiriit Kanatami, the Prince Albert Grand Council and the Athabasca Health Authority. Jeffery et al. indicate the need to move beyond measurement of morbidity and illness to culturally sensitive and sustainable indicators that monitor the health and capacity of communities in order to improve health conditions and quality of life. While important, they also need to be able to provide comparable data that allows monitoring by both communities and their agencies and governments. The current system measures weakness and does not identify strength except in an indirect way as the opposite of weakness. The cultural impetus of the three groups is to view health in a broader way, and to try to develop ways and means of monitoring it. In this way, we begin to create structures and processes that can shape us in positive ways.

All these papers depict communities struggling to act upon their own notions of health, to find ways to create positive individual and collective identities. We are witnessing the emergence of what Duran and Duran call Native American Post-colonial Psychology.³ This emergence is a key element of what I call "post-colonial Indian consciousness," which consists of an awareness of the fact of colonization, knowledge of its effects, a desire to do something to mitigate the effects, and possession of the knowledge, skills and power to carry out one's desire for change. Those living in urban environments are often not seen as engaging in this struggle but as having given up. The narratives that we tell ourselves are important aspects of creating healthy communities and individuals. We may need to alter how we see our pasts as these narratives affect the present and the future.

Adaptable, innovative, healthy, strong, resilient are the words that we need to also add to our vocabulary when describing Aboriginal peoples. They provide an important dimension of health. If we continue to see ourselves only through the lens of woundedness, then we will fail to see what Maslow saw.

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ENDNOTES

1. Edward Hoffman, *The Right to be Human: A Biography of Abraham Maslow*, Edited by Jeremy P. Tarcher (Inc., 1988) p. 123.
2. Ibid.
3. Eduardo E. Duran and Bonnie Duran, *Native American Postcolonial Psychology* (Albany, N.Y.: State University of New York (SUNY) Press, 1995).

'From Woundedness to Resilience': A Critical Review from an Aboriginal Perspective

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Abstract

A critical reflection of the recent call for papers by the National Aboriginal Health Organization permits a greater understanding of what is encompassed in the title 'from woundedness to resilience'. The philosophical basis behind the title reflects a Eurocentric perspective. It is this perspective that places limitations in the sharing of Aboriginal stories of failures and successes. A variety of Aboriginal authors nationally and internationally assist us in engaging in an iterative process in order to deconstruct, reflect, and reconstruct the call for papers. Seeking a decolonized and non-deficit framework facilitates an Aboriginal-centered process that allows the sharing of our urban health and healing stories.

Key Words

Colonization, non-deficit, knowledge, structural analysis

A call for papers by the National Aboriginal Health Organization (NAHO) presents an opportunity to critically explore the theme of *The Health of Urban Aboriginal People: From Woundedness to Resilience*. It is important to reflect on the choice of words used to initiate any discourse around Aboriginal peoples and their health. The implication of the words chosen for this title must resonate from within the experiences of Aboriginal peoples; this intellectual integrity is necessary to influence constructive reflection and change (Agger, B. 1991). The liberal view assumed within the title imparts limited understanding of the complex interplay of the various factors informing the health of Aboriginal peoples in urban communities.

Indeed it sustains the complicity of denial of responsibility by the current systems and how they affect Aboriginal health; 'if only you would take responsibility for your health and healing.' The supposition that we, as Aboriginal peoples, have control over our lives and therefore can impact our health positively is not completely true. This belief fails to acknowledge the influence of colonization on the health of Aboriginal peoples. It defines a deficit model approach whereby we, as Aboriginal peoples, are seen to be solely responsible for our health and healing (Ajwani S, Blakely T, Robson B, Tobias M, Bonne M. 2003). The aim of this paper is to

deconstruct the posture assumed in the theme, reflect critically about the underlying processes informing it and, finally, to reconstruct a decolonized and non-deficit perspective around the health of our peoples.

Although NAHO seeks to expand Aboriginal health knowledge, the call for papers may inadvertently contribute to a silencing of the Aboriginal voices needed to utilize a decolonized construct of health and healing principles alluded to in previous literature (RCAP 1996). The epistemological basis of the title reflects Eurocentric ways of understanding knowledge. (Youngblood Henderson, J. (Sakej). 2000). The hegemonic nature of this non-Aboriginal knowledge paradigm is couched in terms such as rationalism and empiricism and denies the essential components of Aboriginal ways of knowing and understanding. The title implies a fixed and unidirectional temporality in healing. This thematic vector compels Aboriginal peoples to move forward on important matters of health and healing without due reflection.

The philosophical underpinnings that inform the title do not permit the development of an emancipated framework in which we share and learn from our collective grief. These voices, when heard and acknowledged through Aboriginal pedagogies, heal. (Tuhiwai Smith, L. 1999) Reductionism continues to veil the multiplicity of factors (Durie, M. 2003) that inform

our current state of health and healing overtly and otherwise; the impact of racism, oppression, colonization and assimilation continue to implicitly derail a decolonized Aboriginal vision of health.

Our woundedness as Aboriginal peoples is more clearly understood in light of the structural influences that deny our Aboriginality and less so from the individualistic approach to health ascribed to in current western health discourses. Aboriginal peoples neither choose to become diabetic nor do Aboriginal mothers wish alcoholism and early deaths on their children. Yet, we cannot shy away from what the current epidemiological literature tells us. One third of First Nations peoples die violent deaths. (Health Canada. 2003) Some of our young people continue to commit suicide rather than live in a world that systematically denies their very existence. Explain how colonization and the practice of assimilation do not affect our health? More so, detail how many of our people have control over their lives when the balance of power continues to privilege the others? The theme of woundedness romanticizes our struggles and experiences and silences the truth.

The notion of resilience equalizes the metaphorical equation outlining the healing journeys of Aboriginal peoples in urban communities. What does resilience really mean for Aboriginal peoples? We cannot assume to use a word whose connotations may imply Darwinian beliefs of survival of the fittest. This may not sit well with our ancestors. Why is this important? Even now, our people continue to suffer and die younger than the others. What does this mean in the context of resilience? Does this imply a genetic deficiency on our part? Does this mean that those who adapt to the system seem happy, content and productive are somehow better than those of our community who suffer needlessly? Are we able to move our individual community members into a spectrum of resilience? Does this mask a process of turning the gaze away from the systems that continue to perpetuate myths of Aboriginal inferiority? (Razack, S. H. 2001)

Resiliency means self-determination. The Oka crisis and Meech Lake Accord are two prime examples of our political assertion as Aboriginal peoples. Why should we accept the ongoing colonization and assimilation of our peoples? Our present focus must be on how we, as Aboriginal peoples, reclaim our past, present and future. This tacit resilience is found within our Aboriginality. We need not rely on Eurocentric ways of knowing to know ourselves. Thus, from our Aboriginal perspective, resilience is irrelevant. In essence, we must 'turn the gaze back' to the system in order to enlighten ourselves about

its insidious influence upon our collective identity. This is consciencization, an awakening to those things that oppress us. (Freire, P. 1970)

The knowledge about the various structures that impact our state of being and therefore our health are well known (Smith, L.T. 1999). It does not require an iterative process to define its boundaries. Many Aboriginal peoples are well aware of the things that threaten them. Our state of being, as Aboriginal peoples, is implicitly defined and not articulated by our overt actions to the colonial processes, but through tacitly acquired knowledge. (Battiste, M. 2000) Aboriginal peoples need the opportunities to tell their stories. Their ability to express these feelings and experiences however requires an emancipatory framework. The stories of racism and the ability to remain quiet while listening to the pain and the victory underpin healing in the broadest sense. (McWhinney, I.R. 1997)

Predetermined thematic constructs do little to offer Aboriginal peoples valid and culturally appropriate ways of sharing our stories. Not only are the choices of words important, but also the language used to express the story. We must speak about the limitations of the colonial language as a limiting factor in how we are able to express our health as Aboriginal peoples. We are not defined by or within the confines of any colonial language, nor its perpetual construct of privilege for others. (Battiste, M. 2000) Aboriginal academics need to be mindful of the need to be reflective in our work. It is imperative to understand how we may contribute to our continued colonization and oppression. From woundedness to resilience may offer some a chance to share their victories. It is not our intent to silence these stories. Aboriginal academics are accountable to our communities and need to engage in Aboriginal centered peer reviews. We cannot shy away from constructive feedback.

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Community and Culture as Foundations for Resilience: Participatory Health Research with First Nations Student Filmmakers

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Abstract

This article describes a participatory action research project that brings together teachers and students from three First Nations education programs with researchers from the Centre for Youth & Society at the University of Victoria for the purpose of researching health and wellness among Aboriginal youth. Using the methodologies of participatory research, students identify topics that are of concern to them in the area of health and wellness. They plan, research and develop a video presentation on their chosen topic using digital video as a tool for research and communication of their findings. This article focuses on how such an approach to research contributes to building resiliency through the development of relationships that foster a connection with community and culture. The article describes the way the project has enhanced participants' relationships with their communities, across generations, with diverse groups in urban settings, and with their sense of self, and culture.

Keywords

Resilience, health, education, participatory research, First Nations, youth, video, community partnership, relationship, culture

INTRODUCTION

One of the critical social factors found to affect health is that of control.¹ This refers to the amount of control people have over their lives as well as the supportive relationships they have that protect them from isolation and disconnection. The nature of post-modern urban life is fragmentary. Urban Aboriginal populations living in such environments find they are often isolated, scattered and mixed so that they identify with many nations or tribes² rather than a single unique one that is their own. This article explores how a participatory community health research project addresses the disconnection experienced by many urban Aboriginal youth. In the pages that follow, we describe some of the outcomes of the Traditional Pathways to Health project as it relates to the development of relationships that foster resiliency through a connection with community, and the ongoing development of a strong cultural identity.

METHODS

Victoria, the capital of British Columbia, is a

gathering place for a rich mixture of Aboriginal cultures. The classroom diversity represented within this project is broad and includes nine different First Nations across three separate program sites designed to address Aboriginal education. As part of their programs, teachers have partnered with researchers from the Centre for Youth & Society at the University of Victoria to participate in Traditional Pathways to Health, a collaborative research project designed to promote health and wellness among Aboriginal youth. The project is part of a larger federally funded Community Alliance for Health Research (CAHR) called "Healthy Youth in a Healthy Society." Funded through the Canadian Institutes for Health Research, that overall project brings together researchers and community members from a variety of backgrounds to address the topic of injury prevention among young people. In the Traditional Pathways to Health project, students, as co-researchers, choose a health topic or wellness issue that interests them. They then plan, research and develop a video with their message that they later present to their community as a way of sharing what they have learned. This approach is in keeping with conceptions of participatory research that see the presentation of research

findings taking a number of non-traditional (i.e., non-print) forms.³ Another aspect of participatory research that this project draws upon is building capacity within the community and drawing upon the strengths and wisdom held by the participants themselves.

What we mean by health in this project is what the student researchers define as health through their research process. Classroom teachers, school staff and university researchers work with students to facilitate and support the process, which is incorporated into community education programs. It exemplifies one of the ways in which urban Aboriginal people in the Victoria area are working to create resilient individuals and communities.

Programs

Three First Nations teachers in the Victoria area have participated as partners in the Traditional Pathways to Health project. Each runs a course or program that operates slightly differently within the provincial school system to meet the needs of students, which are not being met in the mainstream system. First Nations communities, school communities and the wider community have developed these programs as part of the effort to increase the opportunities and chances for academic success of urban Aboriginal students. All three programs have similar goals and philosophies that ultimately relate to relationship and resiliency.

Careers and Personal Planning at Victoria High School has a course option for Aboriginal students that focuses on making connections with elders and other Aboriginal role models in the community to facilitate their career planning process. The Westshore Centre for Learning and Training has developed a separate First Nations graduation program to assist adult and youth learners. A strong cultural focus engages students in many activities and relationships with Aboriginal artists, poets, dancers, and writers. Provincially required courses are taught in a supportive setting through relationships developed and built upon trust and respect. In First Nations Leadership 11 at Esquimalt Secondary School, the philosophy of the course is based on the belief that students are capable learners, deserving of respect, and are leaders in their lives. It embraces the understanding that First Nations values and beliefs are essential to the understanding of self and others as a leader.

Research project

The specific objectives of the Traditional Pathways to Health project are:

1) to facilitate student investigation of topics that they

perceive to be of importance for the promotion of healthy living and injury prevention

2) to develop strategies for injury prevention and health promotion among young people that are based upon health concerns identified by the young people themselves,

3) to develop leadership skills and research expertise among young people through participation in conducting research about health and wellness, and

4) to develop an understanding of the manner in which participatory action research can be used to develop school and community-based initiatives for health promotion.

The typical procedure in a site project involves the university researchers being invited into the three different First Nations programs described. Initial visits allow everyone to get to know one another, discuss the nature of participatory research, and decide whether they would like to take part in the process of researching and making a video about health and wellness. Permissions and protocols for research (classroom, school, university, community) are discussed with the students. Ethics are linked to and are a reflection of respect, which is a guiding principle of the project. The notion of informed consent⁴ is emphasized as being an integral part of the research process, as is the idea that such consent must be included when students go out and ask people to be interviewed as part of their own research process, even if, or especially if, it involves family members and friends. Exploring topics and planning the video-making process is the next step.

Through large and small group discussion, as well as one-on-one conversations with their teachers and the research team, students develop their ideas around health and then plan how they might get the message across to their audience. Students are encouraged to work with partners or in groups, and organizational skills are emphasized as they prepare to go out into the field and gather information and video footage for their projects. Decisions about who to interview, what questions to ask, where to videotape, and even the desired types of camera shots and angles all come into play during the planning process.

Technical instruction and practice with the digital video cameras are provided by the university team near the beginning of the process so that students are aware of the kinds of things they might want to consider as they plan their videos (i.e., lighting, sound, camera shots, music, interview techniques). Logistical issues concerning equipment use and signout as well as arranging for interviews and getting to interview locations are

largely handled by the students, their families and classroom teachers, though the university researchers sometimes assist with this as well.

Once the students have gathered their video footage, they downloaded and edited their work using computers. In this project, we use iMovie software on Macintosh computers. The program is straightforward and easy to use, which enables the students to concentrate on the information they have gathered and how they are going to put it together to present their message. This part of the process is very intensive and time-consuming.

In one setting (Esquimalt Secondary School), the team has made weekly two-hour visits over the course of two school years for a total of 120 hours of direct contact between the students as community partners and the university research team. The other sites (Victoria High School and the Westshore Center for Learning and Training) have each had a total of 60 hours of direct contact between the university team and the students and teachers in those sites.⁵ Another 60 hours were added from January to June of 2004 at the Esquimalt and Westshore locations.

Twenty-eight student videos have been produced in the first three years of this five-year project. They cover a variety of health-related issues including smoking, drug use and addictions, drinking and driving, suicide, diabetes, the protective effects of culture, cultural dancing, language, healthy lifestyles, participation in sports, racism and discrimination, healing circles, traditional foods and medicines, cultural understandings (wisdom and advice), and relationships.

As part of the participatory structure of this project, student videos have presented to the community in a variety of ways. In their leadership class, students at Esquimalt Secondary School hold a potlatch where they present their video and publicly acknowledge someone in their life who have been of importance to them. Victoria High School and the Westshore Centre for Learning and Training, the other two partner sites, have video screenings for invited family, friends and community members. "These opportunities provide an occasion for students to assume a leadership role within their family and community as they highlight issues that affect the health and well-being of those within their community."⁶ Community members respond publicly to the student presentations and give them feedback on the work they have done.

Students also present their work at other venues. Seven presentations with university researchers have been given to a variety of interested university classes as well as at an international conference. Additionally, university

and/or community partner researchers have given seven conference presentations at the provincial, national and international level. Whenever possible, students are included in these presentations as well to provide an opportunity for them to speak to questions about their work.

Data collection and analysis

Data consists of 28 individual and collaborative student-produced videos, 29 interviews conducted with the student video-makers, and interviews with the three teacher partners. All interviews were recorded using digital video and have been gathered over the past three years, usually at the completion of each school year. As a preparation for analysis of the interview data, video editing software (Final Cut Express) was used to sort and categorize interviews into sequences of questions about the different stages of the project (i.e., planning the video, the process of video-making, reflection on the video's message, and intended effects). These edited video sequences were then burned onto eight DVDs with each interviewee's answers accessible through the use of indexed chapter markers on the individual DVDs. The data sets were then distributed to research team partners for analysis.

For the purpose of this paper, three members of the university research team viewed the interviews and student videos to develop general categories and themes based on interview content. We focused on interview questions that related to the idea of resiliency (see the questions provided in the endnotes referencing specific quotations). After analyzing the respective interview data, each of us did preliminary writing on emerging ideas such as the connection between health and wellness, and culture (including traditional practices such as healing circles, knowledge of self in community), physical activity, building understanding, and passing knowledge across generations. As part of a second pass through the data we viewed the interviews and student videos in a more focused manner, specifically with the topic resilience in mind as a kind of sensitizing concept. We were interested in looking for connections to elements of resiliency as reflected in student interview comments. The notion of relationship came out in many of the interviews; thus our concentration on viewing the data with relationship and resiliency as our focus.

Resilience

... [the experience of doing this video research project] did sort of bring my conscience back

about some of the things I sort of just left behind. I know I've gone through a lot myself and sometimes it doesn't really seem like something that's worth holding onto. I don't know. There's always a reason. I figured I came back for some reason. Just trying to hold my family honour, cuz that's what it's all about.⁷

This quote is from a young adult participant whose video, *Evolution of a People*,⁸ is a powerful tribute to the producer's own Kwakwaka'wakw culture and to all Aboriginal cultures as the foundation for personal identity and strength. If the video was the reason he came back, as he suggests, it is a tribute to his own persistence and resilience as well as his willingness to work to change the persistent social and economic inequalities encountered by his people.

Resiliency can be defined as "the ability to overcome adversity."⁹ Educators look to the resiliency research to support youth in responding appropriately to a broad range of life experiences. "Resiliency is an approach that expands our thinking about students, schools, and communities beyond problem identification and resolution to strengths identification and actualization."¹⁰ Six key elements of resiliency identified by Henry and Milstein (2004)¹¹ are positive connections and relationships; nurturance and support; purposes and expectations; clear, consistent and appropriate boundaries; life-guiding skills; and meaningful participation.

The participatory approach of this project fosters the development of positive relationships and connections amongst the researchers and community members. The relationships between people along with the shared values that link activities, programs, institutions, and communities, are what help us to know who we are and how we fit in with those around us. For the three Aboriginal teachers who are the community partners in this project, relationship is central to their programs, their students and themselves, particularly in this urban setting where many of the students are living away from their home communities. The support and nurturance engendered both in the classroom programs and out in the communities through project work help to develop positive connections with others. In addition to developing relationships, it is important for students and others to learn to both give and ask for the support they need.

The expectations of the First Nations' education programs as well as those of the research project are clear, consistent and appropriate to the needs and abilities of the participants. The school-based programs and the

participatory research project provide a safe and secure place for students to be and work within. All three programs focus on leadership and career planning, which is consistent with the objectives of the Traditional Pathways to Health project. Life-guiding skills need to be developed and applied through experiences such as those that happen throughout the course of this research.

The purposes and expectations of the project are such that students choose and prioritize their own interests and focus of research, which further motivates growth and development of resilient people. Additionally, student, community and university researchers participate in this project in ways that enhance meaningful collaboration with their families, friends and communities. This process enables us to work together rather than in isolation, to contribute or offer something to others, and to, in part, satisfy the sense of responsibility that we all have to give back to the environments and communities that have nurtured and supported us. The approach differs from typical ways of researching health in that it emphasizes a holistic, relation-based framework that not only allows individuals more control over their own health and wellness, but actively engages them in the construction of that wellness by identifying and nurturing strengths. The concept of resilience used in this paper is one that is grounded at a cultural level and is its focused on the relationships that exist between community and culture across generations and geographical settings. In the sections that follow we describe these aspects of the project's outcomes.

RESULTS

Relationship and interaction with others

In an interview with one of the project's teacher partners, Frank Conibear reiterates what he identifies as one of the goals in the First Nations leadership class he teaches. For Conibear, a central concern is that of relationships in community and how that gets developed through involvement with the project.

I think success in an ideal way is how we set it up. It becomes difficult to say, "Okay where is success?" Because that's the ideal, and I think it's more measured in the process of having the students go out and interview different people. Coming up with questions and making that time, beginning a dialogue that's there. And I don't know if we can measure that in the true sense of research. If we really want collaborative research

in the community, it might not be about the product. We can use that to say we've done something, but the real work is, and the real research is, that interaction that the students have with whomever they decide to interview... you know, it takes a long time to get them just to that process. And they still do a public thing [i.e., a presentation], but it might not be a finished product. But they've opened up some doors and I think that's the whole point of the research. Because it isn't about the research... it's about what we can do in our communities.¹²

Conibear acknowledges the standard view of research, and articulates his own appreciation of the ways in which the collaborative research has enabled students to become involved in, and make a contribution to, their own communities. The two other teacher partners also express beliefs about the importance of relationships within communities to strengthen student and personal identity. John Lyall writes,

... So, what is Aboriginal Knowledge to me? Primarily, it is a way of viewing the world. It includes maya'ghila (Respect): respect for yourself, respect for your family, respect for your community, respect for your local surroundings and environment. It includes knowledge transfer, the readiness to accept teachings from your elders and environment and willingness to pass this on through the generations. It includes knowledge, knowledge of your local environment, knowledge of the language, songs, dance, and culture of your peoples. It includes modern dynamics; a capacity to recognize that we are a dynamic people, that we exist in a world different from our ancestors, a capacity to recognize that we must co-exist and survive in a multicultural world. It includes the simple fact that we must recognize how critical it is to keep our teachings alive, that this is our very survival.¹³

Corrine Michel's vision for the project is clear:

I wanted them [her students] to connect with the First Nations community in a positive way. Connecting with community members is important in establishing a sense of identity, especially for urban Natives. Many of the students I work with are disconnected from their cultural

heritage. Some of them are living thousands of miles away from their territory, some have never met their First Nations family members, and some are connected with their culture but are in the city to attend school. They miss being in a space where it is safe to be who they are.

I hoped that they would meet people in the community and perhaps make some connections that would last. I can only speak for myself when I say that there is a profound sense of aloneness that lives inside a First Nations person who is estranged from her family, community and culture. Relationships with other First Nations people helped me to accept who I am, to feel proud of who I am and to understand who I am. When I agreed to participate in the project, I hoped that the students I have the privilege to work with would benefit from this contact with First Nations role models.¹⁴

Student researchers talk about the importance and value of the research project in ways that resonate strongly with their teachers' goals of connecting with community members and building relationships. In their interviews, the students say that they learned from the people they interviewed as they listened to their stories. They heard their point of view, and got to know them better: "...just spending time with my family I guess, I valued the most from [making] this video. And actually seeing them eating the stuff makes me happy. That they're carrying it on, carrying on—the food."¹⁵ This participant's video, *Seafood for Life*,¹⁶ shows how seafood is collected, prepared and shared within her own Pacheedaht culture.

Relationship with other generations

The importance of relationships across generations and the notion of carrying cultural knowledge and traditions forward are reflected in several of the students' comments. The following is in response to the question, "How has this project made a difference in your life?"

... what I kind of came out with most, is how culture is really important to carry on because, it's kinda, it gets covered up by all the media stuff and all the fancy big cities even. It just, it's not as present as I think it used to be and I think it should always be present. I think it's... [pauses]

Culture defines people.... It should be up front; it should be one of the first things people have, on their mind. I don't know, it's just, yeah; it's an important thing to remember.¹⁷

"...there were a few people from outside our community who mentioned taking it [his video] and presenting it outside. Just being able to do that, is probably the most valuable thing."²⁰

Another participant is concerned about the path her sister is on and wants to pass on some of the things about health and wellness that she has learned while making a video about First Nations soccer. Others hope their videos will influence younger (and older) children in positive ways by encouraging them to become more active, to follow a traditional diet, to stay away from drugs and alcohol, and to be aware of the help and resources that are available in the community (i.e., healing circles, friendship centre, diabetes and suicide information, drumming and dance groups, sports organizations).

Personal growth, self-confidence or relationship with oneself are themes that weave throughout the project. Near the end of the term, a participant who had initially said he was not going to do a video decided to do one, and chose to ask people he respected in the community about health and wellness. He talks about the influence his involvement in the project has had on his own well-being.

Well, before this, I wasn't exactly, I didn't exactly know where I was in life. I had dreams, you know, I thought they were impossible, so I gave up on them. I've always said my dream is to make a difference for First Nations people, and I still want to do that now. I feel that I can do it.²¹

Relationship and diversity in urban community

The video project was also seen as important because it enabled people to look at the diversity and relationships within an urban community. Through his research and interviews for his video, one student participant sensed that there are still tensions and inter-cultural rivalries held onto from the past. He points out that in the urban environment, there seems to be some recognition of the need to get along since people are seeing each other every day. Another student videomaker says that the experience of going through the project helped him "to honour and cherish other people's feelings."¹⁸ His work and the video he produced involved working closely with his own group of Esquimalt singers and dancers as well as a non-native ballet company. Several others talk about strengthening the relationships with families and friends as being the most important thing they learned from the project. One student found that the process of doing the project was a good way to make new friends and get more involved in sports, which in turn helped him slow down on his smoking, drug and alcohol use.

Others are inspired to learn. Experience doing research in the community and making their own videos has given student researchers the motivation and incentive to learn more about their families and communities, their culture and their language. One grade 11 student has never been to the reserve where she was born. After completing a video on the advantages and disadvantages of living on and off reserve, she wants to go and find out for herself what it is like, "on reserve, with my family. So, [this project has had] a big influence."²²

Relationship with culture

Many participants talked about and produced videos that reflect the importance of culture and practising one's culture as a way to stay healthy. "When you're involved in your culture, you're a healthier person."²³ They talk about health and wellness as something that is balanced, holistic and reflects how you are in the world.

Relationship and reflection

Feedback from the community was particularly valuable to participants and gives them an opportunity to reflect. Comments made at community presentations had a big impact on their self-esteem and sense of self-worth: "...they thought it was good and I didn't really think it was that good, but, it was great what people were saying."¹⁹ Another student videographer was quite surprised and excited by the response his video caused:

It [culture] brings you spirituality... See now, that's something that's hard to explain unless you experience it, right? So, that's why I'm encouraging people to know their culture, because it does keep you alive. And in your heart, when you walk, when you, just, when you always know you have somewhere you can go to, I think that keeps you alive.²⁴

DISCUSSION

Keeping alive. Definitely a prerequisite for and determinant of health. For these student researchers, knowing and practicing their culture helps to ground them in a strong sense of who they are and where they have come from. For the students and the individuals they interviewed, culture is an integral part of their existence as Aboriginal people. In the words of one of the interviewees in a student video on culture, "It is our *gxleena*, our medicine; it is what makes us strong... If it were not for my culture, I would probably not be here today."²⁵

From the perspective of promoting and improving resiliency, it stands to reason that schools and educators should be doing everything in their power to make sure that all Aboriginal children have the opportunity to learn, know and practise their culture. We can and are working together towards this goal. Partnerships such as ours that include researchers, teachers, community members, and students demonstrate some of the ways that resiliency can be improved by building relationships amongst them. "Resiliency thinking concentrates on why things do work, can work, and will work."²⁶

Nurturing, supportive positive connections and relationships are working for the students and their teachers. The fact that community members were willing to be interviewed and gave their consent to be in the students' videos speaks to the value they place on their relationships with the student researchers. As community members, as family members and as members of their culture, they gave their time and knowledge to help students research and learn about health issues that concern them. Student researchers and community members shared knowledge in ways that resulted in a new and/or stronger relationship between them, as well as a video to be shared and discussed. Involvement in this project fosters the development of positive connections and relationships in many ways. It also fosters resiliency by providing caring environments, high expectations and purposeful support, powerful and effective instruction, and ongoing opportunities for meaningful participation.²⁷

Methodological innovation

At the same time, it is important to appreciate that this project does not conform to standard research practices. In a typical research project on the health of urban Aboriginal youth, the students would be the object or subjects of study. They might be contacted to

participate in a survey, or maybe even a focus group, though it is more likely that they would be mailed or given a questionnaire to complete. Though epidemiological studies serve a useful purpose in medical research, this is not our goal here. In this study, participatory action research approaches are used to involve, engage and ultimately empower student researchers with knowledge that is culturally based, and crafted, in part through their own agency. Students are encouraged to ask questions that help address health issues they see as impacting the youth of their communities. They define and control what they research and how they go about doing it. Using their newly acquired skills as video-makers, they craft the message they want to convey. Focusing on their own families and communities, students create resources for looking at, discussing and managing health. The way in which the research is conducted, along with their developing video and computer skills, enhance the ability and capacity for students to take control of their own health and wellness through processes of knowledge translation. This project is also a contribution toward the ongoing processes of decolonization²⁸ in which Aboriginal peoples replace failed attempts at assimilation with relevant cultural knowledge and practices that are grounded not only in resiliency, but in thousands of years of tradition and survival.

CONCLUSION

Students and teachers alike speak about having the confidence and desire to make a difference in their communities. Making such a difference is related to having another vision for education, health and research while recognizing that the persistence of social inequality and systemic oppression undermines students' full learning potential. By enhancing participants' relationships and building resilient individuals and communities, the Traditional Pathways to Health project takes a step towards meeting this vision. It offers a vision that aims to question, critique and work towards institutional change.²⁹ It is a vision that is about knowledge, relationship and working together. Participating in this project is making a difference.

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Stress-coping Among Aboriginal Individuals with Diabetes in an Urban Canadian City: From Woundedness to Resilience

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Abstract

The purpose of this study was to reveal lay people's views about lived experiences, and meanings of stress and coping with stress among Aboriginal participants with diabetes ($n = 26$) in an urban Canadian city. A framework of resilience was used not only to conceptually ground the study, but also to analytically synthesize its findings. Grounded in a qualitative framework, focus groups were used as the data collection technique, while phenomenology was adopted as an analytical approach. As a key element of woundedness, the study showed that stress is prevalent and plays a significant role in the lives of many participants. Not only are their experiences of stress health-related (specifically, diabetes-related) issues, but their descriptions also suggested that the sources of stress originate from broader structural systems and dynamics at various intertwined levels—socio-economic, cultural, historical, and political. On the other hand, the results indicated that the culturally appropriate use of human strengths and resilience is considered a core meaning of stress-coping among study participants. The key specific factors identified in facilitating this stress-coping process include: using collective strengths, gaining strengths through spirituality, cultivating cultural identity, using personal/individual aspects of strengths, and making positive transformations in culturally meaningful ways. The findings underscore that failing to take into account cultural contexts unique to a particular group will lead to a serious oversight in recognizing both individual and collective aspects, which are essential to a broader and more culturally appropriate conceptualization of the resilience framework.

Key Words

Stress, coping, resilience, strengths, spirituality, cultural identity, diabetes

INTRODUCTION

Exploring in detail the health issues of urban Aboriginal people is both important and timely. First, the focus on urban Aboriginal Canadians is much needed in Aboriginal health research. This idea is supported by and consistent with a major concern raised by the more than 500 Aboriginal and non-Aboriginal stakeholders who participated in the Social Sciences and Humanities Research Council of Canada's (SSHRC) Dialogue on Research and Aboriginal Peoples.¹ In their report, *Opportunities in Aboriginal Research* (2004), "urban issues" are identified as a key Aboriginal research priority/theme. Among the comments by participants were these: "There has been a huge imbalance in research to date . . . Urban issues have been neglected",² "There is very little contemporary scholarship in this area."³

Second, people-oriented and community-based proactive research to explore the nature of both

woundedness and resilience among Aboriginal peoples and communities has important implications for practices, particularly policy-making and the provision of services. In this process, however, it is necessary to reveal the "voices" or views of Aboriginal peoples rather than imposing academic or professional assumptions about their woundedness and resilience. Our research dealt with all of these aspects by exploring the nature of stress experienced among Aboriginal individuals with diabetes in an urban Canadian city, as well as the potential resilience of these individuals and communities to cope with stress. Stress, along with the prevalence of diabetes among urban Aboriginal Canadians,⁴ is considered one key aspect of their woundedness. Proactively coping with stress, meanwhile, is seen as one central element of resilience among Aboriginal Canadians and their communities.

It has been recognized that stress is a defining element of life for Aboriginal peoples with diabetes.⁵

Besides health problems related directly or indirectly to diabetes itself, many appear to have stressful lives, linked not only to day-to-day circumstances (i.e., marginal economic and living conditions),⁶ but also to historical, cultural and political contexts.⁷ For example, based on their findings about the prevalence of diabetes in an urban Canadian city (i.e., Winnipeg), Green, Hoppa, Young, and Blanchard (2003) indicated that its prevalence is “tightly embedded within a context of poverty and disempowerment.”⁸ Also, they reported that the history of colonization and Westernization has had a significant impact on the incidence of diabetes, as well as on subsequent stress experienced by Aboriginal individuals with diabetes. In their participatory action research, Boston and colleagues (1997) showed that Cree people in James Bay of northern Quebec attributed the cause of diabetes to the “white man,” and noted that the spread of diabetes is related to “the decline of bush life.”⁹ According to their ethnographic examination of Aboriginal individuals with diabetes in Melbourne, Australia, Thompson and Gifford (2000) suggested that the lived experiences and meanings of diabetes are tightly contextualized within the broader systems of family, community and society.¹⁰ Furthermore, First Nations participants in Opaskwayak Cree Nation near the town of The Pas, Manitoba, in Bruyère and Garro’s study (2000) viewed diabetes as “rooted in collective experience and in historical processes that have impinged on aboriginal people and are beyond their control.”¹¹ Similarly, Aboriginal participants in two Anishnaabe communities on Manitoulin Island, Ontario, (one rural and one on-reserve setting) in Sunday, Eyles and Upshur’s interview study (2001), considered the cause of diabetes as a collective occurrence closely tied to larger notions of powerlessness.¹²

Within the context of often stressful lives among many Aboriginal peoples with diabetes, it is important to explore ways to proactively cope with stress, rather than considering only the negative consequences of stressful lives from deficit perspectives (i.e., problem-focused, negative perspectives, which tend to blame the victims). There has been some evidence to suggest that many Aboriginal peoples with diabetes have strengths to survive and even thrive, by showing a sense of resilience. For example, one key conclusion drawn from Sunday et al.’s study (2001) was that the incidence of diabetes has brought “the community together,” renewed recognition about the importance of “spirituality, culture, values, traditions,” and, consequently, generated “hope for healing” through “cultural belonging.”¹³

Hence, proactive and effective stress-coping

among Aboriginal peoples with diabetes seems to be an illustration of resilience. Though not specifically mentioned with respect to Indigenous peoples, some researchers have argued the possibility that a framework of resilience is relevant to and useful for conceptualizations of stress-coping.¹⁴ For example, Diener (2003) suggested that “coping is a strength, and good coping represents resilience!”¹⁵

A framework of resilience

Generally, resilience is defined as “the manifestation of positive adaptation despite significant life adversity.”¹⁶ It represents “the ability to survive, and even to thrive, in the face of adversity.”¹⁷ According to Masten and Reed (2002), resilience is an inference about a person’s life that requires two fundamental judgments: that a person is “doing OK or better than OK with respect to a set of expectations for behaviour”; and that “there have been extenuating circumstances that posed a threat to good outcomes,” that is, “the past or current presence of conditions that pose a threat to good adaptation.”¹⁸ It is, however, important to point out that resilience also involves “constructive and growth-enhancing consequences of challenges or adversity.”¹⁹

As emphasized by Glantz and Slobada (1999), “there certainly are people who seem to have resisted or overcome presumably overwhelming problems, obstacles, or stresses, and most individuals report having had this experience at least to some degree.”²⁰ Glantz and Slobada (1999) further explained that “it may be an inextricable part of the ways in which we define and explain not only human behavior but virtually all phenomena with variable outcomes.”²¹ Consequently, one key theme drawn from the emergent body of literature on resilience and human adaptations, highlighted by Masten,²² is that resilience arises from “ordinary magic.” It refers to the idea that:

human individuals are capable of astonishing resistance, coping, recovery, and success in the face of adversity, equipped only with the usual human adaptational capabilities and resources, functioning normally... The literature on resilience suggests that there are some fundamental systems characteristic of human functioning that have great adaptational significance across diverse stressors and threatening situations. These systems are versatile and responsive to a wide variety of challenges, both normative and non-normative.²³

Commenting on the notion of “ordinary magic,” Masten and Reed (2002) summarized, “Resilience does not come from rare and special qualities but from the operations of ordinary human systems, arising from brains, minds, and bodies of children, from their relationships in the family and community, and from schools, religions, and other cultural traditions.”²⁴ It is, however, unknown whether the idea of “ordinary magic” is relevant to people across different cultures or sub-cultures, or whether it is primarily a Eurocentric concept.

Another key attractive and important notion central to resilience research is that it involves “explicit attention to positive outcomes and influences (in addition to negative ones). This can enhance scientific attention to the strengths of groups usually perceived in terms of failures and, concomitantly, can enhance receptiveness to interventions.”²⁵ This notion has practical implications from policy-making and service-provision perspectives. However, one major gap in the emergent body of this research is that only limited attention has been given to the diverse nature of our society, particularly with respect to “cultural contexts.”²⁶ Within Indigenous health research, to date, very limited research effort has been made to directly explore the potential usefulness of a resilience framework from the perspectives of Aboriginal peoples. The exception is a few researchers who have begun to acknowledge the importance of resilience as a conceptual basis of stress-coping among Aboriginal peoples. In particular is Walters and Simoni’s “indigenist” stress-coping model of Native women (2002).²⁷ Here, culturally relevant coping strategies including enculturation, spiritual coping and traditional healing practices are identified as “cultural resilience,” which is proposed to buffer or moderate the vulnerability of Native women who face historical and contemporary traumas (i.e., colonization, discrimination, abuses). Walters and Simoni suggested that it is important to interpret “the vulnerabilities of Native women within the context of their historical and contemporary oppression, while capitalizing their strengths.”²⁸

Purpose of study

The purpose of our study was to reveal lay people’s views/perspectives about lived experiences, and meanings of stress and coping with stress among Aboriginal individuals with diabetes in an urban Canadian city. A framework of resilience was used not only to conceptually ground the study, but also to analytically synthesize its findings. The focus of our

analyses was on exploring the ways in which urban Aboriginal individuals with diabetes proactively cope with stress, by emphasizing their strengths and resilience. Our study went beyond simply analyzing the nature of stress as an element of woundedness in their lives.

METHODS

Focus groups, grounded in a qualitative framework, were used as the data collection technique, while phenomenology was adopted as an analytical approach. Focus groups are recognized as an effective method for obtaining in-depth information about a concept or issue, and learning about people’s experiences.²⁹ Rather than being directed by pre-determined hypotheses or controlled by existing measures (which may not be culturally sensitive), focus groups enable participants to express perspectives, in their own words, in an open and flexible process.³⁰ Furthermore, since focus group sessions bring forward people’s experiences and offer a social context for meaning-making, they more readily allow for an analysis of culture.³¹ Phenomenology, as an analytical framework, aims to explore “what people experience and how they interpret the world.”³² Also, phenomenology focuses on the ways in which members of society experience everyday lives³³ and “how the social world is made meaningful.”³⁴ Generally, the purpose of a phenomenological analysis is to gain insights into the “essence” of a phenomenon under investigation.³⁵

Focus group participants

Posters outlining the research, eligibility criteria and who to contact were displayed at an urban Aboriginal health centre in a western Canadian city. Individuals responding to the posters voluntarily contacted the research assistant, who provided them with additional details on the study. Ethical issues were explained to potential participants. Individuals had to meet some criteria in order to be accepted as participants. They had to identify themselves as First Nations or Métis, and had to have been diagnosed with diabetes. The 26 individuals who met that criteria and agreed to participate were involved in these focus groups: (a) First Nations women with diabetes (n = 8); (b) First Nations men with diabetes (n = 9); and, (c) Métis women with diabetes (n = 9).³⁶ It must be noted that distinguishing Métis individuals from First Nations individuals in addition to the use of female-only and male-only focus groups was based on one key aim of our larger initiative; that is, to recognize the

diversity of Aboriginal peoples. However, the analysis according to these cultural and gender designations is beyond the scope of this paper. Some findings from this element of the analysis are reported elsewhere.³⁷

The participants ranged in age from 26 to 69 (mean = 43.9). Only one participant had completed a university degree, while six individuals had completed Grade 12—the others' levels of education were either less than Grade 12 (sixteen) or were not reported (four). Eighteen (69 per cent) of the 26 participants were unemployed. Three individuals were employed full-time (more than 35 hours/week), two were employed part-time (less than 35 and more than 10 hours/week), and one person was casually employed (less than 10 hours/week). The majority (eighteen, 69 per cent) of the participants reported a yearly household income of less than \$20,000, while the other income categories consisted of five (\$20,001-\$30,000), one (\$30,001-\$40,000), and one (\$40,001-\$60,000) individual(s), respectively. The participants' relationship/marital status varied widely (i.e., ten common-law, six single, four divorced or separated, three married, and three widowed). The average severity of diabetes reported by the participants (on a scale of 1 to 5, ranging from mild to extremely severe) was 3.3. The participants represented a wide range of time periods during which they have lived with diabetes (from 1.5 to 36 years; mean = 12.8).

Focus group procedures

Each session took place at a focus group facility of a local research firm. An experienced and neutral professional moderator, oriented in detailed nuances of communicating with Aboriginal individuals, facilitated all groups. She carefully followed a focus group questioning route,³⁸ developed by the research team and guided by the research objectives. The questioning route outlined opening comments about the topic of stress, introductory questions to engage the participants in the topic, transition questions related to evaluations of stress, key questions on the causes of stress and coping strategies, and closing questions to summarize the discussions and confirm main points. (Please refer to Table 1 for the specific questions asked and the probes used for inquiring about the nature of stress and coping.) The moderator reminded the participants at the beginning of each focus group session that the purpose of a focus group is not to reach consensus, but to openly share one's viewpoints. At each stage of questioning, the moderator created a comfortable context and gave sufficient time for all participants to express their views.

At the conclusion of each focus group, the participants completed an exit questionnaire to provide socio-demographic background information. They were thanked for their time and contribution to the focus group and each was given a \$50 honorarium. Each focus group lasted about 90 minutes as planned. The research assistant transcribed verbatim the conversations of the focus groups.

Data analysis procedures

Phenomenological data analysis was conducted. First, the principal researcher (Yoshitaka Iwasaki, co-author of this paper) identified statements separately for each group about how the participants were describing the phenomena (i.e., stress and coping), and listed every significant statement relevant to the phenomenon (i.e., "horizontalization" of the data; Moustakas, 1994).³⁹ Next, these statements were clustered into themes or meaning units, separately for each group, by removing repetitive and overlapping statements.⁴⁰ These meaning units were formulated by reflectively reading and re-reading the full transcripts to ensure that the significant statements were consistent with the original context. Through this process, the researcher assessed whether anything was not accounted for in the clusters of common themes, and ensured that the proposed clusters did not include interpretations that exceeded the original context of the data.⁴¹ This process resulted in a refinement of the theme clusters, which were then referred back to the original descriptions for further validation.

Based on the previous steps, the principal researcher developed summary statements separately for each group, along with selected original quotations from the transcripts to illustrate the relevance of the summary statements. The other researcher (Judith Bartlett, the other author of this paper) critically reviewed the analysis process and results. She has Métis heritage and is an expert in Aboriginal qualitative health research with very extensive practical and research knowledge and experiences in Aboriginal health issues. She provided comments, which were incorporated to revise the categorizations and descriptions of key themes. Besides data analyses, Bartlett has played a key role in every step of our research to make sure that the research process is culturally appropriate by acknowledging Aboriginal viewpoints and worldviews. Major comments raised by the researcher necessitated re-analyzing part of the data and more critically interpreting some of the findings. Finally, both researchers confirmed that the analysis was appropriately carried out and that the results were

Table 1. Focus group questioning route used

Opening Comments:	<ul style="list-style-type: none">• Welcome and statements regarding the purpose of the study, focus group procedures, and ethical issues.
Opening Question:	<ul style="list-style-type: none">• Please tell us a little bit about yourself.
Introductory Question:	<ul style="list-style-type: none">• Stress is prevalent in our everyday lives because many people feel stressed. In thinking about your daily life, what does stress mean to you?
Transition Questions:	<ul style="list-style-type: none">• Is stress a negative factor in your life? If so, explain how it is negative.• Is stress a positive factor in your life? If so, in what ways it is positive? Probe: What is it about stress that makes it good or bad?
Key Questions:	<ul style="list-style-type: none">• What are the things that contribute to stress in your life? <i>Probes:</i> (a) How does this work, does one thing contribute to stress more than others or does the combinations of many things contribute to stress? (b) Do you have any particular health concerns that contribute to your feelings of stress? Can you tell us more about this? (c) Besides possible health concerns, is there anything else that adds to your feelings of stress? (d) Does being an Aboriginal person contribute to your feelings of stress? If so, please describe how. <ul style="list-style-type: none">• What are the ways or strategies that you use to help you deal with stress in your daily life? <i>Probes:</i> (a) How would you describe your typical way of coping with stress in your life? (b) Do you use any spiritual and/or physical means to deal with stress such as the use of elders, churches, exercise, or playing with grandchildren? If so, please describe how.
Ending Questions:	<ul style="list-style-type: none">• All things considered, what would you say is the major cause of stress in your life?• Of all the ways of dealing with stress that we've talked about tonight, which have you found to be most useful in your life?• Is there anything about stress and coping that we haven't talked about that you would like to raise before we leave tonight?

consistent with the data. The revised summary descriptions were sent to the participants as a member-checking approach. Those participants who returned their evaluation forms (16 of the 26 individuals, or 62 per cent) unanimously verified that the descriptions were consistent with the views they originally expressed in focus groups.

RESULTS

Stress: an element of woundedness

Our analyses of data about the lived experiences and meanings of stress described by our participants highlighted that stress is prevalent in their lives ("Stress is something that we live with every day," said one

participant). In particular, many individuals indicated that living with diabetes has a substantial impact on their lives at various levels. First, at a physical level, the stress of managing diabetes involved limiting one's diet and daily activities, and dealing with symptoms (i.e., chronic "pain") and medications. For example, one woman said, "Having to watch what you eat, watching your sugars. That's real stress. I had to give up a lot of stuff I like to eat. Also I'm not able to do the things I used to be able to do," while another woman admitted, "My health is deteriorating already. I take lots of pills and it's hard, it's stressful for me."

At a psychological level, however, the stress of living with diabetes included denial, worries, helplessness, and/or stigma about the illness. For example, one

female mentioned, “My family worries about me. I guess there is a lot of denial for me. You don’t want to believe that you have it [diabetes],” whereas describing a feeling of helplessness, one woman said, “It’s hard for me to control my sugar and I feel sorry for myself. I don’t know who to turn to.” Also, diabetes is a major concern at a family level (rather than simply at an individual level), as emphasized by one male. “In my house, diabetes passed on through my family, so there is that stress.” In addition, many participants described the stress resulting from complications related to or caused by diabetes, including loss of a leg, loss of sight, kidney removal, or an enlarged liver. Several individuals talked about unemployment as a stress factor due to disability caused by their illness. As one male noted, “That’s how come I lost my job.”

Besides living with diabetes, the stress experienced by the participants is embedded in broader structural life contexts—socio-economically, culturally, historically, and politically. For example, socio-economic factors raised include poverty (i.e., “money problems”) and poor living or housing situations. As described by one pregnant woman, “Stress for me is where I live. I live with 25 other pregnant women in a small place.” Illustrating cultural, historical and political influences, the specific stress factors identified deal with cumulative aspects of their lives being linked to the history of colonization and Westernization, and the discrimination toward Aboriginal individuals. Participants vividly described evidence of “deep-rooted racism” in historical and contemporary contexts, from school settings and communities (i.e., negative “preconceived notions” about Aboriginal peoples) to government programs (i.e., aggressive law enforcements to convict Aboriginal offenders) and employment practices (i.e., “go for some job you won’t be able to get because you’re Native”). The following quote from one Aboriginal man reflects this:

I have to run to the school every time they’re trying to put my child into a program, a “learn how to speak English” program, because they have an accent. You face these kinds of racism, deep-rooted racism, that even the teachers don’t even understand... The North End is considered the core area, but we have a lot of different people, immigrants that came into [Winnipeg] in the early 1900s, and Native people are just a minority there, in the North End. But when they refer to the North End, the majority is “drunken Indians” or something like that. That small percentage of the gangs is a good example....

They sure can go after the Native gangs, like the Manitoba Warriors. They put into a \$4 million prison, just so that they can convict them—that was a waste of money. They should have done something better with that money. You see these kinds of things all the time.

Further commenting on a broader structural life context, another man raised the difficulty of living in “two worlds”—the Aboriginal communities versus an entity consisting of the dominant groups of Canadians. This point implies that the issue here is not just “identity” per se at a micro or individual level, but societal or systemic influences at a macro level. For instance, some Aboriginal individuals with diabetes described cumulative stress due to their traumatic experiences in residential schools, which in some cases, resulted in lengthy lawsuits. In fact, one man considered his “residential school lawsuit against the federal government for seven years” as “long-term stress.” In another example, “recalling” her forced attendance at a residential school and the abuse that occurred there, one Aboriginal woman stated, “I don’t want them [my children] to suffer the way I’m suffering.” Clearly, these examples illustrate that the stress experienced by Aboriginal peoples is not only concerned with personal issues, but also is closely and extensively tied to structural aspects at historical, cultural and political levels.

In addition, another woman disclosed that some parents were unwilling to reveal their children’s Métis identity, perhaps because they grew up in an era when Métis were stigmatized. This has had a significant impact at cultural and political levels in a broad macro sense, as well as at a personal level in a micro sense.

I’m a Métis woman being caught up in the child welfare system and all that history being taken away, taken away from families. When I went for the search of my Aboriginal heritage, it was stressful to find out the information and to figure out who you are. Even my parents didn’t want to say that they were. So I go do that search, because that’s my generation. Anyways I know what I am. And that can be stressful when it becomes political and somebody is looking for identity. I did get my genealogy right down to the 1800s.

Coping with stress: human strengths and resilience

Despite the stressful and sometimes traumatic experiences of most participants, they widely and often

enthusiastically spoke of their strengths in dealing proactively with stress, which demonstrated a “survival spirit” and sense of resilience. Notably, the use of collective strengths was raised frequently among participants. To illustrate this aspect, one woman emphasized the importance of gaining culturally appropriate support from a group of Aboriginal people who shared similar life challenges, including living with diabetes:

Belonging to groups, just for get-togethers. They’re all my culture, they’re all Native. Even just going sitting there, listening to them talk. I always come home with such a light feeling because they share so many wonderful stories with me, and it makes me feel good and happy. And it’s nice to be with them.

By realizing that they are not alone and that everyone supports each other in a culturally meaningful way, these individuals appeared to become more knowledgeable about issues central to their lives (including dealing with diabetes), to be able to identify and then use their personal and collective strengths to deal with stress, and to become more hopeful about their lives. Clearly, this is an example of a potential linkage between stressors (i.e., diabetes-related) experienced by Aboriginal peoples and an attribute of resilience, illustrating how strong and resilient they are in coping with the stressors.

Gaining strengths through spirituality is another key factor raised by many participants because spirituality is “sacred” and “fundamental” to Aboriginal peoples, as exemplified by the following quote from one man:

Being Aboriginal or Native or Anishnaabe or Indian or whatever you want to call us, it’s hard living in two worlds. The spirituality part, it’s sacred to us and we have to learn it. I think that’s what’s keeping me going now.

This description suggests that spirituality plays an important role in dealing with living in the “two worlds” (the Aboriginal world versus the dominant Western world) emphasized previously, a major source of stress at a broader structural level. This is another example of how a resilient attribute (in this case, spirituality) can help Aboriginal peoples deal with stress in life.

One woman also mentioned that a church-based recovery and support group plays a significant role in her life and acknowledged church as a “safe place” and a “place of refuge.” This group provides Aboriginal individuals with an opportunity to openly talk about their lived experiences (including diabetes-related issues):

Just to talk and deal with what’s going on in our lives and why we have our problems, where they stem from. And to deal with those from wherever it may be, from childhood or as an adult, abuse or whatever. To get right down to where the root of the problem is.

A spirituality-guided strength in a group setting seems very effective in educating themselves—about challenges in life and how to deal with these—in a culturally appropriate way, to gain support from others, and to have confidence and hope for their lives. Again, this exemplifies the role of a resilience- and strength-related attribute that Aboriginal peoples use in coping with stress.

Another source of resilience and strength indicated by the participants involves cultivating cultural identities. In speaking of “sweat lodges” and “powwows,” one participant said, “This is part of our heritage. I feel good about seeing what I see.” Other examples illustrating this notion included: (a) being involved in “projects” (i.e., “recreat[ing] the oxcart trail,” “building the carts like in the old days,” “sav[ing] the Métis cemetery”), which gives encouragement when one is “feeling down” and provides a sense of purpose; (b) educating one’s children about Aboriginal history and showing them traditions such as Aboriginal tea and dances as a way of coping/healing (i.e., “we dance together, that was a lot of fun.”); (c) doing “a lot of Native arts,” which gives a sense of “satisfaction” and accomplishment; and (d) “genealogy” done for oneself and one’s children (“it’s interesting because I really get into it. I have to go to the Archives and all that. That’s my generation. Now I know what I am.”) Assuring cultural identities of Aboriginal peoples as another strengths-based attribute seems to have a positive impact on dealing with stress in their lives.

Along with the importance of collective and cultural strengths, participants talked about personal or individual strengths in coping with stress. For example, one woman noted that she looks after herself through proper techniques such as diets and “physio”-therapy because she “wants to live,” while one man indicated that

he has “learned to control” diabetes and “learned to be able to live with it.” Another woman concurred: “You learn how to cope with what happens. I think it’s about how to cope with the different things that come up. You learn.”

Demonstrating another aspect of human strengths/resilience was the constructive use of humour or laughter which was also identified as a stress-coping strategy. For example, two men mentioned laughter as an important healer, which was taught by their elders:

I think one of the positive things that you can look at is what the elders say, there’s one good healer and that is laughter. Having fun. I think that is a positive one.

Well, laughter is a big healer when you’re down and out. My grandparents, they’re gone now, and one of the things that they taught me is, when you have a problem you have to talk about it and also put a little bit of laughter in it. And it heals. Laughter is a big thing.

The use of humour or laughter here appears to have a more culturally meaningful connotation compared to the Western notion of humour.

Additional ways of coping with stress that participants identified included culturally appropriate forms of physical activity such as Aboriginal dancing (“I think dance is really important to relieve stress. You try to jig for a couple of hours. It takes away stress”), as well as escaping from the city and urbanization:

Too many people have problems, getting mad and screaming at each other. So I need my time-out. It’s nice to get away to forget about everything in the city. I don’t think about the awful things and try to think better.

I go for a drive out in the country with his family because I like to see trees and nature where I came from.

Again, it is important to acknowledge a unique cultural context in which physical activity (i.e., Aboriginal dancing) and getting away from the city (i.e., being with and in harmony with nature) operate rather than just at a behavioural level from a Western perspective.

Furthermore, participants’ descriptions suggested that the realization and utilization of personal and

collective strengths through stress-coping has the potential to be transformative. For example, one woman indicated that as a way of dealing with stress, she “quit doing the things that made [her] really stressful” including “quit drinking” and “changed [her] friends.” She admitted that these “changed [her] life” very positively. Also, as mentioned earlier, one woman who regularly participates in a church-based recovery and support group admitted that the experiences gained from this group transformed her in a positive and meaningful way since it provides an important setting/context within which to discuss solutions for dealing with the challenges or difficulties people face in their lives. In addition, another person pointed out that besides its stress-relieving benefit, a massage helps one experience positive feelings physically, emotionally and spiritually, and provides an “opportunity to go within [herself],” implying the potential of a massage to be transformative. Once again, there is the need to recognize a cultural context and meaning associated with this transformative process because the basis of this transformation appears to be linked to Aboriginal peoples’ cultural and spiritual orientations.

DISCUSSION

Our study provided evidence illustrating some of the central factors directly linked to the theme of from woundedness to resilience. The study showed that stress, a key element of woundedness, is prevalent and plays a significant role in the lives of many participants—Aboriginal individuals with diabetes living in an urban Canadian city. Not only are their experiences of stress health-related (specifically, diabetes-related) issues, but their descriptions also suggested that the sources of stress originate from broader structural systems and dynamics at various intertwined levels—socio-economic, cultural, historical, and political. In particular, their experiences of stress are closely embedded within the history of colonization and Westernization, and are caused by cumulative and structural discriminations (i.e., racism). Distinct from the popular conceptualizations of stress in the dominant mainstream literature, which tends to focus on micro/individualistic sources of stress,⁴² the findings underscore the need to give greater attention to macro/structural sources of stress, which tend to have cumulative effects on individuals and their communities.

On the other hand, our findings showed that the framework of resilience is useful in gaining a better understanding of stress-coping among urban Aboriginal

individuals with diabetes. Overall, the results indicate that the culturally appropriate use of human strengths and resilience is considered a core meaning of stress-coping among study participants. One key factor that facilitates this process is the use of collective strengths, which emphasizes interdependence or connectedness. Another central factor highlighted is gaining strengths through spirituality, a “sacred fundamental” for most participants in their lives. Cultivating cultural identity also was identified as a major source for gaining or building strengths. It is important to emphasize that the descriptions made by the participants deal with both collective and personal/individual aspects of strengths. Consequently, the combined/converging use of both types of strengths was shown to have the potential for positive transformations in culturally meaningful ways.

Despite the usefulness of a resilience framework, the present findings suggest that it is important and necessary to understand human strengths and resilience as a core meaning of stress-coping within cultural contexts. Specifically, the findings indicate that culture plays a central role in explaining the nature and meanings of stress-coping strategies used by urban Aboriginal individuals with diabetes. In fact, all of the specific ways in which these individuals cope with stress, demonstrated in this study, have important cultural meanings or connotations—whether these are tied to collective strengths or spirituality, or to cultural identity, individual strengths or positive transformations. Our participants’ views about the ways of stress-coping illustrated how essential culture is in better understanding these aspects, as well as how the specific coping strategies are tied closely to their cultural contexts. These findings challenge the current narrow views of resilience frameworks, which have been based primarily on ethnocentric thinking and perspectives.⁴³ Although there appear to be some fundamental common characteristics or properties of resilience that may be shared by or relevant to all human beings, regardless of cultural differences,⁴⁴ failing to take into account cultural contexts unique to particular groups will lead to a serious oversight. Individual and collective aspects essential to a broader and more holistic conceptualization of the resilience framework will not be recognized.

A major gap in this research area has been the dominance of quantitative methods, particularly survey methods with the use of rather ethnocentric measures.⁴⁵ Simply including non-dominant cultural group members in a large-scale survey study does not solve this problem unless the measures used have been validated as

appropriate to the cultural contexts of particular non-dominant group members, and unless the research process acknowledges the characteristics and life circumstances of communities/cultural groups. As demonstrated in the present research, it is important to use a methodological approach that incorporates the process for explicitly “revealing” the insights or “voices” of individuals who live in a particular cultural context; namely, the use of qualitative methods such as in-depth interviews, focus groups or case studies. Our research represented one of the first studies aimed at “listening to” and “uncovering” the voices or perspectives of urban Aboriginal individuals about the nature of stress as an element of woundedness, and the ways of stress-coping as a reflection of resilience.

Recently, some researchers have shown how a resilience framework can foster a better understanding of the use of human strengths for positive adaptations to life adversities. For example, Balsam (2003) identified “unique strengths and resilience factors”⁴⁶ among sexual minority women, while Bowleg, Huang, Brooks, Black, and Burkholder (2003) provided empirical support for a resilience model in their study on black lesbians.⁴⁷ Also, Kimhi and Shamai’s study (2004) on individuals who have lived close to the Israel-Lebanon border highlighted “the importance of perceived community resilience as an individual resource for coping with the threat created by war and terror, thereby connecting between micro- and macro-levels in events related to political violence.”⁴⁸ Though limited in scope, Aboriginal health research has begun to acknowledge the potential usefulness of a resilience framework. For instance, the findings from Sunday et al.’s study (2001) in two Anishnaabe communities on Manitoulin Island, Ontario, implied the importance of “spirituality” and “cultural belonging”⁴⁹ for healing from or coping with the experiences of living with diabetes. Also, Walters and Simoni (2002) aimed to reconceptualize Native women’s health by proposing an “indigenist” stress-coping model of Native women, which included “cultural resilience” factors such as enculturation, spiritual coping and traditional healing practices.⁵⁰

CONCLUSION

Although our research did not specifically ask questions about the uniqueness of urban living among Aboriginal individuals, at least one aspect of our findings implied the importance of giving attention to such uniqueness. In particular, some participants talked about

escaping from the city and urbanization as a way of coping with stress. Perhaps living in an urban setting may create an additional source of stress, unique to urban dwellers, compared to Aboriginal individuals who live in a non-urban (i.e., rural, on-reserve) setting.

It must be noted, however, that our intention here is not to generalize the findings, given the very specific nature of the sample used with a relatively small sample size. Although the use of purposive-criterion sampling is justifiable within a qualitative framework, further efforts will be required to better understand the use of human strengths and resilience in coping with stress among Aboriginal populations worldwide. As shown in this research, these efforts should acknowledge the cultural contexts in which Aboriginal peoples live from both micro and macro perspectives, along with the recognition of individual and collective strengths. Taking into account the cumulative effects of their socio-economic, cultural, historical, and political factors is also a must. For the purpose of appropriately recognizing human resilience processes, “strengths-based approaches” should be adopted rather than “deficit-based approaches.”⁵¹ One often neglected but important idea about strengths-based approaches, however, is that “the promotion of strengths can reduce risk for problem outcomes,” as argued by Sandler, Ayers, Suter, Schultz, and Twohey-Jacobs (2004).⁵² Specifically, they pointed out that:

The goals of building strengths and preventing problems are synergistic: A policy that promotes strengths may also provide the most sustainable and effective approach to reducing problem outcomes.⁵³ ...Public policies can provide resources that promote the development of enduring individual, family, and community strengths and that counteract the effects of adversities (emphasis added).⁵⁴

At this point it is still premature to encourage policy-makers and program-developers to simply adopt resilience- and strengths-based approaches, given the paucity of research evidence to inform policy-making and provision of services from the perspectives of Aboriginal community-based research. However, we are both hopeful and optimistic that if our efforts to conduct meaningful research with Aboriginal peoples and communities continue, well-designed, rigorous research (i.e., community-based, participatory action research) will provide a coherent collection of credible findings to

become a basis/foundation for more effective and meaningful policy-making and service-provision for Aboriginal peoples and their communities. Our research, as an element of our larger research initiative, appears to be a good, albeit small, step toward achieving this important goal. At the minimum, any research should acknowledge and incorporate the voices and views of Aboriginal individuals in the research process.

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Personal Health Practices Around Physical Activity as Perceived by the Aboriginal Children of Prince Edward Island

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Abstract

During the past decade, there have been several health surveys involving Canada's Aboriginal people. In many of these studies, the Aboriginal population of Prince Edward Island (P.E.I.) has not been adequately represented. Given the lack of information regarding the health status of this population, the Abegweit and Lennox Island First Nations bands collaborated with the University of Prince Edward Island's Faculty of Education, School of Nursing, and Department of Family and Nutritional Sciences to gain a more comprehensive profile of the perceptions, health behaviours and needs of Aboriginal children living on reserve in both of these Island communities.

The study focused primarily on three of the determinants of health: early childhood development, education, and personal health practices and coping. Individuals from the two P.E.I. communities were interviewed, including 18 children in the 6-8 year age group, 22 children in the 9-12 year age group, 28 youth in the 13-18 year age group, 27 parents or caregivers, and 6 pregnant mothers. This research is important as there is little, if any, research undertaken with the Mi'kmaq communities of P.E.I. Unique features of this study are the inclusion of children as informants, the use of a multidisciplinary team and the active involvement of the Mi'kmaq community in all stages of the project.

The purpose of this article is to disseminate some of the personal health practices around physical activity as perceived by the Aboriginal children and to identify current health behaviours and/or needs of active, healthy lifestyles. Therefore, only the results focusing on these children's perceptions of their health, and their perceptions and behaviours about physical activities, will be discussed.

Key Words

Prince Edward Island, Aboriginal children's health, perceptions, community, multidisciplinary, physical activity

INTRODUCTION

Background information

In the past several years, there has been a renewed interest in the health of Canadians with a particular focus on the health of Canadian children. While the majority of children in Canada are healthy, certain groups, like Aboriginal children, are considered

more vulnerable.¹ According to the Canadian Institute of Child Health (CICH), "the general health status of Canada's aboriginal population ranks below the national standards for all other populations."² Approximately 50 per cent of Aboriginal children, both on and off reserve, live in poverty.³ The prevalence of chronic diseases such as diabetes, cardiovascular disease and cancer is higher in the Aboriginal population than in the

general population, and appears to be increasing.⁴ While statistics regarding the health status of Aboriginal populations are discouraging, more comprehensive information about Aboriginal health and factors affecting it are needed to facilitate appropriate planning and policy decisions. Current statistics regarding Aboriginal health reinforce the importance and urgency of identifying culturally appropriate ways to improve the health and well-being of this population.

One of the traditional approaches to addressing physical inactivity has been to focus on individuals' awareness of the benefits of physical activity and to use this to change behaviour. However, recent research has demonstrated the importance of social, physical and cultural environments in determining the extent to which people are able to be active in all facets of daily life, including work, education, family life, and leisure. Modifying the aspects of social, physical and cultural environments that pose barriers to physical activity and enhancing those that are supportive will make active living an easier choice for Canadians.⁵

Research approaches in this project are based primarily on the involvement of P.E.I.'s Mi'kmaq people in identifying their perceptions of their children's health and physical activity needs. Through the articulation and documentation of Mi'kmaq children's perspectives on health, researchers believed that a vision would emerge that could provide recommendations for future interventions, directed and owned by members of the communities. In this way, Mi'kmaq people would identify the issues and challenges they face in their efforts to build a healthy community.

Present state of knowledge

The benefits of regular exercise have been well documented and include outcomes such as improved cardiovascular functioning, lowered serum cholesterol and serum glucose, decreased body fat and weight, increased stamina, decreased stress levels, improved self-esteem and reduced risk of cancer, diabetes, heart disease, and osteoporosis.⁶ Poor lifestyle habits, including physical inactivity, are major contributors to increased adult morbidity and mortality from chronic illnesses. Over the past decade there has been an increase in sedentary lifestyle and obesity in children and adolescents, both in North America and worldwide.⁷ Approximately 28 per cent of Canadian youth aged 15 to 19 are deemed to be physically inactive.⁸ In addition, only 46 per cent of Canadian children between the ages of 5 and 17 satisfy the energy expenditure guideline for

optimal health and development (8 kcal/kg/day).⁹ A higher proportion of girls are inactive at all ages, such as during adolescence, when there is a significant decline in physical activity among youth. At 5 to 12 years of age, 30 per cent of girls are physically active compared with 50 per cent of boys; at 13 to 17 years of age, these statistics drop to 25 per cent and 40 per cent respectively.¹⁰

In addition to a lack of physical activity, there has been an increase in such sedentary behaviour as watching television, and using video games and computers. In the fall of 2000, Canadian children watched an average of 15.5 hours of television a week, while youth aged 12 to 17 years watched an average of 14.1 hours weekly.¹¹ Ninety-eight per cent of American households in 1998 had a television and the number of households with two or more televisions has increased dramatically.¹² American children aged 6 to 11 watch an average of 23 hours of television per week.¹³ Television watching is associated strongly with an increased risk in obesity because it involves both a decrease in energy expenditure and an increase in energy intake by excessively eating snack foods high in fat and calories.¹⁴

Video and computer games are becoming more popular for children and youth. In 2000, 4.7 million Canadian households were connected to the Internet and 71 per cent of households reported that at least one person in the home regularly used the Internet at least seven times weekly.¹⁵

Little is known about the levels of inactivity and their risk factors among Canada's Aboriginal people.¹⁶ It is known, however, that Aboriginal people have undergone drastic lifestyle changes: from a lifestyle of high activity and relatively low energy intake, to a lifestyle of low activity and relatively high energy intake.¹⁷ Furthermore, although the prevalence of cardiovascular disease (CVD) has been declining in Canada, there are data to suggest that CVD rates are increasing among Aboriginal people.¹⁸ This higher prevalence has been attributed to glucose abnormalities, abnormal lipids, hypertension, tobacco use and obesity as a result of inactivity.¹⁹ The erosion of the traditional ways of life among some Aboriginal people has resulted in the reduction or elimination of the need to fish, hunt or trap in order to survive, leading to a more sedentary lifestyle.²⁰

METHODS

Research objective

The objective of this research project was to explore perceptions of Aboriginal children who live in

the Lennox Island and Abegweit communities on Prince Edward Island regarding health and the determinants of their health. Another objective was to identify the current health behaviours and health needs of these children.

Research questions

Specific research questions for this project were: What are the perceptions of P.E.I. Mi'kmaq children regarding their health, and the determinants of their health? What are the children's and parents' perceptions about strengths and specific health and educational needs of these Island children? What are the health behaviours of Mi'kmaq children on P.E.I.?

Methodology

The research was exploratory in nature. The research project was developed in collaboration with the Mi'kmaq communities of Lennox Island and Abegweit, with chiefs of both communities endorsing the research. The research team consulted with the communities to ensure the research project was meeting their needs. In keeping with the recommendations of the Royal Commission on Aboriginal Peoples (1996),²¹ research approaches in this project were based primarily on the involvement of the Mi'kmaq of the Lennox Island and Abegweit communities in identifying their perceptions of their children's health, health behaviours and needs. By supporting the articulation and documentation of Mi'kmaq children's perspectives on health, the researchers believed that a vision would emerge that could provide recommendations for future interventions directed and owned by members of the communities.

The research included qualitative and quantitative methods. Qualitative data were collected regarding the children's and parents' perceptions of children's health, health behaviours and the determinants of their health through in-depth case studies. Self-reports and interviews with caregivers and key informants were used to collect quantitative data regarding specific health behaviours. The research proposal was not designed to gather health-based statistical information. Reducing health disparities among Aboriginal individuals and communities is fostered by greater understanding of how to enhance their strengths and resilience. While Aboriginal communities have relied on health research and medical science to reduce health disparities, they also have relied on their own psychological, organizational and cultural assets and strengths to survive major harms and disruptions over centuries and to rebound.

This research approach recognizes that the values, beliefs and standards of action that shape contemporary Aboriginal lifestyles must be understood within a dynamic context. Many of the factors that affect children's health are beyond the direct control of health services as the determinants of health involve a complex array of social, economic and personal factors. A major premise of the research is that social context, such as relationships with families, friends, school acquaintances, and community members, influences health and health-related behaviours of young people. Understanding the context is essential to guiding efforts to modify health behaviours. One of the hallmarks of the research is the independent measurement of such contextual influences on child and adolescent health through interviews with children and parents, and through collection of data on community and school-level characteristics.

Sample

The study sample was all Aboriginal children between the ages of 0 to 18 years (approximately 225 in total) and their parents, as well as pregnant mothers from the Lennox Island and Abegweit communities. The aim was to have 140 children and their families participate. This figure would represent the population with a .95 confidence level.²² A concerted effort was made to ensure both genders were adequately represented. Interviews were conducted with each child aged 5 to 18 years, as well as with one primary caregiver per child. Interviews were also conducted with the primary caregiver for each child aged 0-5 years, with all pregnant mothers, and with key informants in the communities.

Data collection

The communities had requested that data be collected through interviews, as they preferred to share their perspectives face to face. Interview guides were developed by the research team in collaboration with an advisory group consisting of Aboriginal community members, community health representatives, and school representatives. Age appropriate interview guides were developed for children in the following age groups: 5-8 years, 9-12 years, 13-15 years, and 16-18 years. The appropriateness of the interview guides was determined through expert consultation, community input and feedback, and the piloting of the interview protocols with at least three children and adults in each group. Separate interview guides were developed for pregnant mothers, the primary caregivers for children 0-5, the primary caregivers for children 5-18 years, and key informants in

the community. The interview guide included structured and semi-structured questions regarding children's perceptions of health, the determinants of their health, and health behaviours.

Interviews were conducted in the home or place of choice for the child and caregiver and lasted approximately 30 minutes for younger children and not more than 60 minutes for older children and caregivers. During a single meeting, each study participant provided demographic information, participated in an audiotaped interview to share personal perceptions of health and determinants of health, and responded to structured questions regarding health behaviours. All interviewers received extensive interview training and ongoing mentoring and monitoring from the researchers.

Prior to seeking consent for individual interviews, researchers and research assistants went into the communities to promote the research project and to get to know community members. By hosting events such as strawberry socials and pizza parties, and by participating in organized community events such as health expos, powwows and holiday gatherings, the research assistants were soon familiar figures to children and parents alike.

Ethical consideration

The research proposal was reviewed and accepted by the University of Prince Edward Island Ethics Board. Study participants were assured that their participation was voluntary and that they could withdraw from the study at any time. Written consent was obtained from parents and adult participants as well as from the children themselves. The consent forms for all participants were written in plain language and read to the participants.

Data analysis

The interviews were transcribed verbatim from the audiotapes and analyzed using content analysis. Qualitative data were analyzed according to manifest content; that is, statements were taken at "face value" rather than attempting to make inferences about what was intended. Interviews were then coded using NUD*IST. Themes, perceptions and patterns of behaviour at different ages were identified.

RESULTS

Recruitment into the study resulted in 101 individuals from the two communities being interviewed, including 18 children in the 6-8 year age group, 22

children in the 9-12 year age group, 28 youth in the 13-18 year age group, 27 parents or caregivers and 6 pregnant mothers. In order to more easily describe results, participants in the 6-8 year age group will be referred to as "children," participants in the 9-12 year age group will be referred to as "adolescents" and participants in the 13-18 year age group will be referred to as "teens." The purpose of this article is to explore some of the personal health practices around physical activity as perceived by the Aboriginal children, and to identify current health behaviours and/or needs of active, healthy lifestyles. Only the results focusing on these children's perceptions of their health and their perceptions and behaviours about physical activities will be discussed.

Children's perceptions of health

You should like who you are... You should be happy with what you are doing... And if you're not, then you're not mentally healthy, and if you're not mentally healthy then you get disorders, and then you're not physically healthy. (Male, 17.)

When asked, "How healthy do you think you are?," most of the children and adolescents considered themselves to be healthy (see Figure 1). There was a significant decline in the teen group, however, with only 43 per cent perceiving themselves to be healthy.

Figure 1. Children's Perceptions of Their Own Health

	6-8 Year Olds	9-12 Year Olds	13-18 Year Olds
Healthy	88%	93%	43%
Unhealthy	12%	7%	36%
Somewhat healthy	—	—	14%
Unsure	—	—	7%

Although the specific reasons for this percentage decline is unknown, there is information on what children believe keep them from being healthy. Participants' perceptions about things that may be unhealthy include not eating the right foods, not exercising, not taking care of one's body, and high risk behaviours such as smoking, drinking and using drugs (see Figure 2).

I don't think smoking is healthy 'cause it makes you get cancer; my nana got cancer... my mom and daddy smoke in the garage, but not me. (Female, 7.)

Smoking and alcohol and drugs aren't good for you, they aren't healthy... because when you smoke it gets into your lungs; it's called second smoke. (Female, 9.)

I don't smoke 'cause it's gross... it kills you... smoking, doing drugs and drinking are all unhealthy. (Male, 15.)

Drugs mess up your life but you know alcohol will mess it up too. (Female, 16.)

Figure 2. What Keeps A Person From Being Healthy

	6-8 Year Olds	9-12 Year Olds	13-18 Year Olds
Smoking	88%	86%	76%
Eating junk food	71%	64%	48%
Drinking	18%	59%	52%
Not exercising	12%	23%	—
Not taking care of one's body	18%	59%	52%
Using drugs	—	64%	62%
Engaging in risky sexual behaviour	—	—	10%

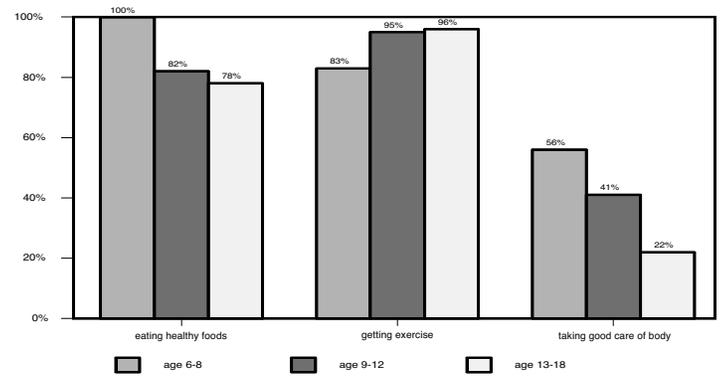
When the participants were asked what can keep them healthy, most responded that eating healthy foods and getting exercise are major components of being healthy and reported both exercising and eating properly as ways to keep healthy (see Figure 3).

Healthy means being strong... doing exercise, eating healthy things like corn on the cob. (Male, 7.)

Healthy means being in shape, eating right, not smoking, not drinking or doing drugs. (Male, 15.)

Healthy means avoiding drugs and alcohol. Not being angry, keeping it cool. (Female, 16.)

Figure 3. What Can A Person Do To Be Healthy



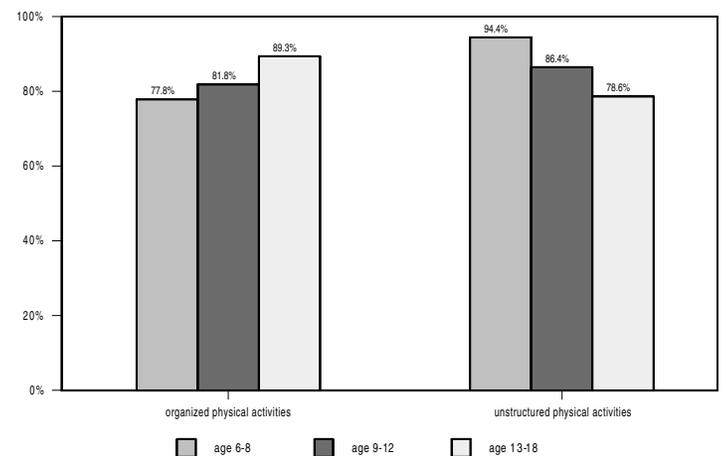
Physical activity

That was awesome, I was really proud of myself. I even finished in the race, going there and training. Waking up right early to train. I was really proud of myself. (Female, 16.)

Participants in all three groups reported strongly that health was achieved through structured and unstructured physical activities. It is significant to note that those in the teen group reported higher participation in structured activities (see Figure 4).

The various structured and unstructured physical activities that children of the three age groups are involved in are of interest for program development. Planning physical activities that children are engaged in will ensure successful participation (see Figures 5a and 5b). Children reported that they enjoy participating in physical activities.

Figure 4. Level of Involvement in Physical Activities



I was happy when I went skating with my dad, but they kept falling down... it was fun. (Female, 7.)

I play hide-and-seek with my cousin and my friend when we go out for recess. (Female, 6.)

I'm happy when I'm working out, playing basketball with my friends... (Male, 15.)

I'm happy when I'm boxing... (Female, 17.)

Figure 5a. Structured Physical Activity

	6-8 Year Olds	9-12 Year Olds	13-18 Year Olds
Soccer	64%	50%	16%
Hockey	48%	50%	48%
Basketball	43%	41%	60%
Martial Arts	21%	28%	8%
Baseball	16%	17%	16%
Boxing	—	—	28%

Figure 5b. Unstructured Physical Activities

	6-8 Year Olds	9-12 Year Olds	13-18 Year Olds
Playing games	47%	37%	—
Skating	41%	—	27%
Biking	35%	42%	23%
Swimming	29%	47%	36%
Walking	18%	47%	36%

Participants reported that engaging in physical activities makes them proud. Again, however, this percentage was significantly reduced in the teen group (see Figure 6).

I felt proud when I won a medal... for a soccer goal. (Female, 7.)

When I won races I felt proud. (Female, 10.)

Boxing makes me feel proud for sure. (Female, 17.)

Figure 6. "Participating in Sports/Physical Activities Makes Us Proud"

6-8 Year Olds	9-12 Year Olds	13-18 Year Olds
59%	46%	18%

DISCUSSION

Most participants in all age groups perceived physical activity as a means to being healthy and were involved in structured and unstructured activities. The younger children were involved in various unstructured activities, whereas the teens participated in more structured programs. There is also a strong perception that physical activities can be used as protective factors against high-risk behaviours such as drugs, alcohol and smoking.

... sports like boxing, judo, intramurals... I think it gets them away from the bad stuff 'cause it gives them something to look forward to. (Female, 17.)

I decided not to take them (drugs) anymore, it ruins my lifestyle. (Male, 15.)

This correlation is supported by the literature that states that children who enjoy full and active lives are much less likely to turn to self-destructive behaviours such as alcohol and drug abuse.²³ Furthermore, skills developed Participating in physical activities build confidence, self-esteem and feelings of success. Thus, physical activity can reduce the effects of the challenges facing Aboriginal children. Children who feel good about themselves, through participation in physical activities, function more effectively and productively in families, schools and communities. Therefore, involving communities to work together toward the development and maintenance of facilities and programs should be encouraged. Recommendations to enhance participation in physical activities can be made through family and community involvement, and also through policy change.

Families

Families should be counselled to reduce sedentary activities by limiting exposure to television and video and/or computer games. An achievable first step is

to reduce these activities by 30 minutes/day, and subsequently allowing up to 90 minutes/day for these activities. Parents could be encouraged to enroll their children in age and developmentally appropriate sports and recreational activities. Youth, themselves, should be encouraged to get involved in promoting physical activities for their peers. Events should include a wide variety of weight-bearing activities as part of sports, recreation, transportation, chores, work, planned exercise and school-based physical education classes. Activities should be fun and unstructured for best compliance. These guidelines are part of *Canada's Physical Activity Guide* (www.paguide.com) for healthy active living for children and youth, a credible tool to encourage children and youth to be more active.

Communities

Community mobilization refers to a process whereby a community becomes actively involved in solving community problems.²⁴ Increasing community awareness of and improving attitudes toward healthy lifestyles are key objectives for supporting community mobilization. Individual health behaviours are reinforced or hindered by social or physical environmental factors. Examples of such community mobilization efforts would be the development of comprehensive community and sport recreation programs that use the community and school facilities after hours. These may make recreation programs available to more children since they could be offered at reasonable costs and would be equally available to both sexes.

Creating active school communities is an essential component of a healthy active lifestyle. An active school community is one in which all citizens, including teachers, students, parents, administrators, and community leaders, work together to create physical and social environments that support active, healthy lifestyles.²⁵

Initiatives should be undertaken to provide children and youth with quality daily physical education classes and health education programs led by qualified, trained educators. Initiatives should also provide the use of school-based sports facilities for after-school hours. The curriculum for the health education programs would contain sections on nutrition, fitness, diabetes, understanding the human body, and healthy lifestyles.

Policy-makers

Emphasis should be placed on the construction of safe recreational facilities such as playgrounds, parks,

bike paths, sidewalks, and roads. Children and youth should be provided with safe recreation facilities that are stocked with appropriate equipment, ensuring exposure to a wide range of physical activities, especially those encouraging lifestyle changes.

The reinstatement of compulsory physical education throughout all age groups in all schools is highly recommended. School physical education programs and extracurricular physical activities could play a significant role in improving students' attitudes, discipline and behaviours.²⁶ In fact, reducing the number of hours spent on physical activity actually hinders educational performance and there is modest evidence that shows that physical activity actually enhances academic achievement.²⁷

CONCLUSION

I feel, we, as a community, have been crying for our voices to be heard and our tears are not just to be wiped away. Let us work together for our future children. (Community Member)

The purpose of this article was to explore some of the personal health practices around physical activity as perceived by certain Aboriginal children, and to identify current health behaviours and/or needs of active, healthy lifestyles. Through the articulation and documentation of Mi'kmaq children's perspectives on health, researchers believed that a vision would emerge that could provide recommendations for future interventions directed and owned by the members of the communities. In this way, Mi'kmaq people would identify the issues and challenges they face in their efforts to build a healthy community. Physical activity can be used as a protective factor to reduce the effects of these challenges.

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Our Health, Strengthened by Sharing

Urban First Nations People with Disabilities Speak Out

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Abstract

This article presents the findings of a two-year exploratory study that examined the challenges identified by First Nations persons with physical disabilities in a western prairie city-Regina. The rate of disabilities among Aboriginal people is 32 per cent, which is twice the national average. Research groups conducted with First Nations persons with disabilities sought qualitative data regarding the daily barriers these people encounter. A First Nations researcher and an Elder used a traditional style of "sharing circles" to collect the data and ensure that their voices and perspectives were clearly articulated. Findings from this study suggest that urban First Nations people with disabilities are not living an independent lifestyle and are excluded from participating in community life. They live in poverty and isolation, and do not access many of the services and benefits to which they are entitled. The participants identified practical recommendations to eliminate or overcome some of the obstacles. There is a need for a thorough policy and program review of the conflicting jurisdictional issues and, to initiate change, there is a need for a strong and effective voice that includes Aboriginal persons.

Key Words

Urban Aboriginal people, First Nations peoples, physical disabilities.

INTRODUCTION

The old man said, to have been born imperfect was a sign of specialness... The old man explained carefully that in the old days, if a child came with a hare-shorn lip, it wasn't a terrible thing or a hurtful thing; it meant the child's soul was still in touch with the Spirit World. (Yvonne Johnson, 1996.)

Yvonne Johnson's tragic story has been vividly told in the emotionally charged book, *Stolen Life, The Journey of a Cree Woman*, where much of her grief and sorrow has been related to a seemingly minor disability.¹ Her voice is clearly heard in this book. However, it is rare that the perspectives of First Nations persons with disabilities are heard; their voices are often lost or ignored. This article presents the results of an exploratory qualitative study examining the issues facing First Nations persons with physical disabilities living in an urban prairie community.² In this article, the voices and perspectives of these special people are presented in a culturally sensitive manner that accurately reflects their

experiences. This research study identifies the social and economic barriers to independent living and offers recommendations for change. In this article, the term "Aboriginal" is meant to include all persons who identify themselves as First Nations, Métis or Inuit, and First Nations applies to those individuals who hold status under the *Indian Act*.

Canada has a population of over 32 million people, of which approximately five million have a disability; this figure represents 16 per cent of the population.³ Using Statistics Canada scale, most adults with disabilities have mild disabilities (47 per cent), while 32 per cent have moderate disabilities and 22 per cent have severe disabilities.⁴ In Canada, 817,300 adults or four per cent of the total population have disabilities that are severe. The rates of disabilities increase with age and are higher among women.

The estimated First Nations population, both on- and off-reserve in Canada, is 638,445 (Canada, 2001) and the population of persons identifying themselves as Aboriginal is over one million. Previous research has shown that 32 per cent of Aboriginal people reported a disability, which is twice the national average.⁵ Although

Aboriginal people have congenital disabilities at about the same rate as the rest of the Canadian population, they have a higher rate of environmental and trauma-related disabilities. "The disparity between Aboriginal and non-Aboriginal rates of disability corresponds to disparities in rates of injury, accident, violence, self-destructive or suicidal behaviour, and illness (such as diabetes) that can result in permanent impairment."⁶

In addition, Aboriginal people suffer higher rates of specific diseases, such as Type II diabetes, which has been recognized as "one of the most serious chronic diseases among Aboriginal populations in Canada."⁷ The rates of Type II diabetes vary from 1.5 to three times the average of the rate of Canada's overall population. These rates have serious implications for the prevention of disability, as well as education and service delivery.

Existing programs and services for Aboriginal people with disabilities are confusing and complex, and many individuals simply fail to receive entitled services and programs. In recent years, Canadian Aboriginal people have been assuming greater control over their social and health programs, including rehabilitative and support services, which have implications for access and service. Little is known about Aboriginal persons who have a disability and are living in urban communities.⁸

Considering this lack of knowledge and the high rates of disabilities among Aboriginal people, the researchers wanted to understand the reasons Aboriginal people with disabilities are not visible in their urban community.⁹ They wanted to discover the perspectives of Aboriginal people regarding independence and the barriers to social inclusion. As well, the researchers sought recommendations from First Nations people with disabilities that would aid in their pursuit of independent living, especially considering the increasing band administration of health and social programs.

METHODS

Social research is political and, historically, it has been used as an instrument of exploitation and oppression against Aboriginal peoples.¹⁰ However, there is a need for quality research that provides a "voice" and can lead to improved policies and programs from all levels of government. The researchers actively sought culturally appropriate methods and built partnerships of equality throughout the study.¹¹

The first step in recruiting participants began with identifying Aboriginal people with disabilities, creating a non-random "availability sample." Our

community research member was able to provide a resource/contact list of suitable participants. Upon her recommendation, participation letters describing the researcher's background and the nature of the study were mailed out to 12 individuals. Because most Aboriginal people hold oral traditions, letters alone are not a good strategy in recruiting Aboriginal people and personal telephone calls were made to follow up and encourage participation. The combined strategy was found to be successful in creating the groups.

Data collection

The focus group, with traditional customs, was chosen to provide the opportunity for participants to share their personal experiences. The use of the focus group format was based on its resemblance to a traditional form of sharing within Aboriginal communities. As well, it adheres to the principles of participatory research.¹² An Elder provided counsel pertaining to traditional procedures for sharing circles. According to the Elder, the circle generates power among the participants; through positive discussion, positive power is created. In this sense, the research group provided participants with the opportunity to contribute to a discussion and to wield some power or, in more basic terms, experience some sense of worth from their contributions. Based on the sharing circle concept, each participant was provided with the opportunity to speak and to be heard. For many Aboriginal people with disabilities, the opportunity to speak and to be heard has not often been afforded to them. Although they may have spoken in other situations, their concerns have not always been heard. Sharing circles promote healing through sharing with others who have similar perspectives or experiences. The focus group sessions provided the participants with the platform to tell their personal stories and to receive comfort from other group members. This process created a level of healing for some of the participants.

The researchers, who had the approval of the University of Regina Research Ethics Board, were careful to apply culturally appropriate and ethical research practices. Participation was voluntary and confidentiality was maintained. All of the participants were adults and there were no conflicts of power/interests. Informed consent was achieved after careful explanations of the purpose and process of the study, including the full right to withdraw at any time. Each participant signed a consent form. All of the sessions were audiotaped and transcribed immediately after each

session. A list of general questions was prepared prior to the sessions but discussion was often spontaneous, building on previous ideas. The transcripts were carefully analyzed and through coding, themes emerged.

Prior to conducting the circles, the researcher had to establish trust with the participants. To address the issue of trust and any reluctance to participate, the researcher took the necessary steps to explain the nature of this research study. Also, the researcher took the opportunity to provide the group with her personal information. It was explained that the researcher was a First Nations person, from the interior of British Columbia, who had personal experience with the various restrictive barriers that limit or interfere with independent living. The researcher established a bond with the group not only based on her ethnicity, but also because of her experiences with social institutions and debilitating barriers. Given this commonality, the group was able to establish trust quite readily. They reported that they felt free to express their own perspectives rather than giving responses they believed that the researcher might have been expecting. This added to the uniqueness and strengths of the study and provided a basis for research validity.

Participant backgrounds

In the four sessions conducted, only four members of the 11 participants consistently attended while the others attended only one or two sessions. All the participants either had a moderate or severe form of physical disability, or lived with someone who had a disability. There was representation from both sexes, and ages ranged from 20 to 50+ years. All of the participants began life able-bodied and without disabilities. They acquired their disability in their adult life as a result of accidents, medical conditions, violence (weapons and physical/spousal abuse), substance abuse (needle use), poor housing conditions (dilapidated stairways), and/or chronic diseases (arthritis). Of those who attended all four groups, one female was employed full-time, one male was taking retraining and receiving an income supplemented by a pension, and two males were “unemployable” and receiving their income from social assistance and living in private apartments. Seven individuals lived in rental homes, family dwellings (with parents or other family members) and rehabilitation/long-term care facilities. Overall, the participants relied on taxi services or the para-transit bus system as their main source of transportation. One participant was fully mobile, while three individuals utilized wheelchairs for mobility (one motorized, one ventilator- or mouth-

operated, one manual). Mobility was the most prevalent limitation, followed by hearing and speech disorders. Other disabilities included diabetes, arthritis and poor muscular control as a result of an acquired brain injury. There was no effort to exclude non-status Aboriginal persons; however, as it turned out, all the participants were First Nations (status Indians). They had originally lived on their home reserve, but with the lack of services for people with disabilities, found it necessary to relocate to an urban centre to access programs and services. Because urban non-status and status persons live under similar circumstances, most of the findings have been cautiously generalized to both groups.

RESULTS

The emerging themes have been organized under the following headings: Independent Living; Barriers to Independent Living; Transportation; Employment and Income; Education and Training; Housing; and Personal Supports. The following quotations are a collection of the participants’ thoughts and perspectives.

All of the participants in this study were forced to leave their home reserve in order to receive services. Many moved to the city alone and were not familiar with an urban setting. They did not know where to obtain services, and the services available did not always meet their needs. Unfortunately for status First Nations people, jurisdictional responsibility for the provision of services creates a myriad of problems. For example, a simple repair to a wheelchair might involve Medical Services of Health Canada, Indian and Northern Affairs Canada and the band administration. First Nations people with disabilities felt they were shuffled from one government agency to the next because of jurisdictional disputes between the various levels of government. The complexity of funding responsibility makes it extremely difficult for First Nations people with disabilities to understand their entitled rights to services and benefits.

Independent living

People with disabilities are working on the issues facing independent living in (*this city*) but they consistently encounter barriers to full and meaningful employment. Like with the attendant care issue, the government is totally against having individual funding for attendant care. (Female, 35, quadriplegic.)

All the participants were confident in their understanding of independence, citing that it represented the ability to be able to live a lifestyle that allowed for individual choices and decision-making. They felt strongly that they needed to be afforded the same access to services as able-bodied individuals, free from restrictive barriers. There was group consensus that they would have a more difficult time achieving independence than other people with disabilities because they were also discriminated against on the grounds of being of Aboriginal descent.

One participant stated:

Being disabled is one thing, but being disabled and Indian is a whole other problem. Indian people do not have a very good reputation and it makes it hard on us to get ahead. The bands don't want to help us once we leave the reserve, and the services in the city might not help you because they don't get funding for you. Also, if you are applying for a job, some employees are racist; so are some landlords. (Female, 51, agility.)

Whether due to a mobility, sight or hearing loss disability, the participants were dependent on others to assist them in their daily functioning, ranging from total dependence (quadriplegic) to partial dependence (hearing or sight loss). The goal of living completely alone was not realistic. However, the group felt that being dependent on others for physical assistance did not mean that individual choice should be restricted.

With the exception of two group members, the majority indicated that they did not have a sufficient income. One member stated that after buying food, paying the rent and other bills, little monies were left for social or recreational outings. Because of insufficient funds and the need for a support person, this individual had to live with an aging family member. Another group member stated that, even though living in a rehabilitation facility meant that a person's food and shelter were covered, there was no money left to purchase personal items such as toiletries, clothing, gifts, and entertainment. In order to live with some dignity, her family had to cover these additional expenses.

Because the participants were living off-reserve and in the city, they received social assistance under the disability benefits program from the provincial government. The program provides limited funds and although they do not like the provincial program,

they feared band-administered programs could be worse.

According to R. R. Gadacz, independent living refers to the ability to be full participants in the community.¹³ However, the group identified that without an adequate income, employment opportunities, educational and training programs, adequate transportation, and support services, First Nations people with disabilities could not achieve independent living. Since most of the participants were without a sufficient income and did not have adequate access to support services, many of them have abandoned their dream of living independently. They have resigned themselves to the fact that having a disability and being Aboriginal means a lifetime of dependency and hardships. This feeling of hopelessness was repeated in each session, and there was little anticipation that circumstances would change. Feelings of hopelessness and despair not only developed over the individuals' disabilities, they also were a result of the continuous struggle to access resources and services when there are ingrained social barriers limiting full participation in community life.

Barriers to independent living

Barriers are physical and social obstacles inhibiting people with disabilities from full active community participation.¹⁴ These barriers can affect every aspect of the physical and social environment, engulfing attitudes, institutions, language and culture, service delivery, and the power relations and structures of society.¹⁵ The lack of personal input and control over their lives is the central problem.¹⁶ Barriers are created, not necessarily intentionally, by and for able-bodied people, and perpetuated by attitudes and images based on concepts of dependency, which are even further reinforced by the professionals who act as gatekeepers of services and support.¹⁷ As such, people with disabilities have been restricted from the decision-making process, whether it be in regard to their person or to the policies that affect and control their lives.

Any barrier denies equal opportunities and full participation in community life.¹⁸ Social and physical barriers are repressive, such that many people with disabilities are forced to deny their experiences and their reality of disability, and conform to the prejudices and images imposed by others.¹⁹ These attitudinal barriers contribute to feelings of low self-worth and social isolation. Many individuals are trapped in a self-depreciating world of loneliness and hopelessness, and other associated problems.

As one participant reflected:

I didn't accept my disability for a long time, probably five years. I went through drinking a fair bit, drugs and it was the only way I could cope with life. I wanted to be *out to lunch* all the time and not really care about myself. But then after a while I needed to take a really good look at my life and I don't want to be like this for the rest of my life, so then I started... I stopped drinking, stopped doing drugs, stopped trying to be so dysfunctional. I found better ways to handle my disability. (Female, 35, quadriplegic.)

Aboriginal people have never had the benefit of being full and active participants in mainstream society because of restrictive social and physical barriers. Unfortunately, these widespread barriers have restricted their access to resources, economic opportunity and services. Aboriginal people have been confronted by repressive policies that have perpetuated limited access and created a state of dependency on the government.²⁰ Aboriginal people with disabilities are undoubtedly affected two-fold: first, as a result of their ethnicity and, second, because of their disability. Because of stereotypes and discrimination, Aboriginal people with disabilities have had negative connotations attached to their culture and disability.²¹ These attitudinal and systemic barriers have made it even more difficult to integrate into full community participation. With restricted and limited access to resources and services, Aboriginal people with disabilities are forced to remain in a dependent role, having few of their basic needs met which, make it extremely difficult to attain independence.²²

Transportation

Access to transportation affects a person's ability to be independent in a number of ways. Without adequate and reliable means of travel, a person with a disability is restricted from participating in many aspects of community life, such as shopping, employment, education, training, medical appointments, and recreation.²³

If I have to wait for two days to book a ride, I don't get out that much, especially in the winter. Since getting around is either tough or costs too much, I tend to stay at home a lot. That affects a lot more than just not being able to get out of my

apartment. I start feeling closed in and get down on myself. (Male, 36, agility.)

The participants listed para-transit, public buses, taxi cabs, personal/family vehicles, and their wheelchairs as their transportation systems. All agreed that transportation was not always readily accessible or reliable. According to the participants, the transportation systems in this city presented a major barrier to independent living. Depending on the disability, public transportation was not easily accessible for people with physical disabilities, especially for those who rely on wheelchairs. City buses do not have lifts or voice activators giving destinations and, therefore, the individual must rely on other forms of transportation. Since the para-transit system normally requires a 48-hour advanced booking, the alternative options are limited.

Central to the issue of transportation is access and affordability. If a reliable means of transportation is not affordable or accessible, Aboriginal people with disabilities are limited in their ability to participate fully in community life. As such, employment opportunities may be forfeited if the person is unable to get to the destination without encountering barriers.

Employment and income

The impoverishment of physically impaired people arises out of the fact that, as a group, we are excluded from the mainstream of social activities... The particular form of poverty principally associated with physical impairment is caused by our exclusion from the ability to earn an income... This exclusion is linked with our exclusion from participating in the social activities and provisions that make employment possible.²⁴

Part of being independent is the ability to support one's self economically. The ability to be economically self-sustaining, in turn, depends upon success in the labour market. It has been estimated that the unemployment rate for Aboriginal people is up to four times higher than that of other Canadians.²⁵ The rate of unemployment is even greater for Aboriginal people with disabilities, much for the same reasons, but also because of stereotypes and discriminatory hiring practices.

Research indicates that those who are fortunate enough to have employment tend to be concentrated in lower-skilled, lower-wage employment sectors.²⁶

Participants who were previously employed before their disability commented on the physical barriers within workplaces that did not allow for a comfortable or accessible work environment. Such barriers consisted of low desks and counter tops that did not allow for wheelchair clearance, cramped work quarters, inaccessible washroom facilities, and non-adaptive technology. One participant stated:

Accessibility in the workplace and attendant services are necessary for me. If they are not available or accessible, then I am pretty restricted to where I can work. (Male, 36, agility.)

Another individual commented on the inflexibility of some employers to allow for attendant services.

Some employers are uncomfortable with disabled people and even more uncomfortable with having an attendant present. With those kinds of attitudes, it makes getting a job pretty hard. (Male, 32, family member speaking on behalf of male, 25, hearing and speech.)

Education and training

For many group participants, education was viewed as a necessity in obtaining and securing employment. All group members did have some secondary education, and over half of the participants had completed high school. Depending on when they developed their disability, a number of the participants had attempted some employment training programs. While education and training were deemed necessary, securing funding for it proved to be difficult.

I'm continually fighting for education funding and training. I keep searching for a job but there are none with my experience and education level. But the band does not want to give me any sponsorship because I live off-reserve. (Male, 36, agility.)

All the participants stated that their individual bands were reluctant to provide funding for upgrading, vocational training or retraining programs. Without funding, many of the participants were unable to utilize programs that would be beneficial in preparing them for entry and re-entry into the labour market. The group members stated that efforts to secure funding were met

with resistance and refusal. Those who challenged the system were unprepared for the lengthy negotiating processes in which the individual generally lost.

According to the funding arrangements between the federal government and band governments, status Indians living off-reserve may be excluded by the bands and many are reluctant to support band members living off-reserve. Since a high percentage of First Nations people with disabilities are forced to move to urban centres, their likelihood of receiving band sponsorship is slim. None of the participants in this study were satisfied with their band government. Individuals must search for alternative funds because the bands refuse support.

The Neil Squire Foundation (employment and training non-profit agency) helped with my funding so I could get computer training because the band would not support me. So after two years of fighting (with the band) for some funding, I finally received help from the organization (Neil Squire Foundation). (Male, 36, agility.)

Housing

Housing is not a problem for those who can afford it. It is not a question of the availability of adequate housing, but the problem of affordability caused by poverty. The group indicated that affordable housing was substandard and of poor quality.

What is needed is an allocation of more accessible and affordable housing to people with disabilities... but usually their definition of wheelchair-accessible is just a ramp to the door. They don't take into consideration that you need to use your chair to go into the washroom. Washrooms are so small in most apartments. Like getting under the sink. I can't do it where we live. I just wash up on my lap every day with a basin. (Female, 35, quadriplegic.)

One of the participants commented that many rental units were alleged to be accessible and suitable for persons with disabilities but, clearly, they were not. In addition, comments were made on the practices of some landlords taking advantage of renters with disabilities.

The house I live in does not have a back door, steps or a porch... it's just a drop and that is not safe. The landlord won't fix my entrance. The

doorway is a struggle to get through, but the landlord says it's wheelchair-accessible. He just keeps saying he has no money to do any renovations. Landlords use welfare people... This house, I got it fixed up to be wheelchair-accessible just to be able to get through the front door. He used the grant money to do renovations but did them sloppy to save the money for himself. (Female, 51, agility.)

There was group consensus that accessible and affordable housing was a problem, and frequently there were limited choices as to where participants could reside. Some of the participants stated that they could not afford to rent in the more attractive locations in the city. Generally, they were concentrated in the core area of the city where rent was cheaper, but housing conditions were poor and neighbourhoods were not fully safe.

Personal supports

According to the participants, personal supports such as attendant care, equipment repair, service provision, and counselling were supposed to be included but these benefits were difficult to access. All the participants indicated that, without supports an individual suffers, not only physically, but also mentally and emotionally. Emotional support is crucial to an acceptance of one's disability, and a lack of acceptance can inhibit the individual's willingness to adapt to a new limitation.

For participants with restricted mobility, the provision of attendant care was a growing concern. As identified by the participants, family frequently fulfilled the role of caregivers though they did not receive any monetary compensation for their work. According to one participant, funding was not available for caregivers if they were family members. Badly needed respite care was not an option because of the inability to provide funds. In addition, family members could not claim any expenses associated with attendant care.

There is not any compensation for the family and that's who you rely on or that's who you have to rely on. The family system can *burn out* really fast without help, and that has a big effect on the disabled person. (Male, 36, able-bodied.)

Another participant stated:

About care-giving, it's really lacking... I know (my husband) took a care-giving course three

years ago. They started having their meetings and after a while everyone started saying they just didn't have the time because they had people at home they had to look after and there were no supports in place to help out during those times, when they had to be away from home. (Female, 35, quadriplegic.)

One participant stated that although there continues to be a lack of services, there have been improvements.

I think it's getting to be more so now, because 20 years ago when I became disabled there wasn't any of those supports but now you can get somebody in for peer counselling. Like if I wanted, like if I was newly injured and I went through Rehab, they would send somebody up to see me from CPA (Canadian Paraplegic Association), if I wanted... which is really good that they (support services) recognize there was a void and they needed to do something about it. (Female, 35, quadriplegic.)

DISCUSSION

Self-government means the ability and inherent right of Aboriginal people to govern themselves as they decide, creating and operating their own social, administrative and economic institutions. The pursuit of independent living for Aboriginal people with disabilities is similar. In light of the group's experiences, there are serious issues with *self-government* through increasing band administration of social and health programs. All of the participants stated that they were not receiving adequate support or services from their band administration, which forced them to move from their families and community to the urban centre. One participant recalled a story of an elderly woman with a disability living on the reserve who was not receiving any support from her band.

One woman living on the reserve was getting \$99 for living and she really had nobody to do her attending except for her 10-year-old grandson. When my sister went over to visit her, her springs were sticking out of her bed. That's a terrible situation. Yet she wanted to live at home and I guess she could have opted to go to a hospital or a group home, but then you're taking away her

choice if she was forced to go live somewhere else. (Female, 40, congenital disease.)

For many, it is a continual fight to receive even meagre assistance because of a lack of understanding of disabilities amongst chiefs and band councils. One participant stated:

When I moved home to my reserve after I became disabled, I had to fight for a ramp. For the first months I was home, I had to go up five steps, so it took three people to take me out or back into the house, which is really silly because what if there's a fire and no people around, you could be in pretty big trouble. (Female, 35, quadriplegic.)

The participants indicated that disability issues are not viewed as a priority by the chiefs and band councils and, with increasing band administration, people with disabilities will be further marginalized.

Disabled people will altogether be forgotten about, because right now we are at the bottom of the pile, but with self-government we won't be in the pile at all. They aren't concerned with the disabled, they're more concerned with making money. Even though they are supposed to get additional funding for the disabled, we don't see any of that. (Female, 35, quadriplegic.)

Another participant argues:

It is necessary for the bands, more specifically, chief and council, to become aware. Chief and council are not very supportive because they are not aware or because disability issues are just not a priority to them. But that's where it starts because they could start creating services like counselling services and attendant services. They need to be willing to allocate money. Nowadays you hear about all those reserves getting land claim dollars back, you think they would have some dollars to help disabled band members. (Female, 35, quadriplegic.)

Overall, the participants feared that they will be further ignored as funding of services and programs is transferred to band governments. It was suggested that they would be better off without status.

From the discussions, the participants identified and listed the following 11 recommendations.

1) Awareness programs for both Aboriginal and non-

Aboriginal people need to be developed and delivered by Aboriginal people with disabilities. By creating social awareness of the barriers, steps can be taken to rectify problems.

- 2) There is a need for increased funding to cover the cost of disabilities. The social conditions that Aboriginal people with disabilities have to endure need to change. A sufficient and dependable income could improve the standard of living.
- 3) Monetary compensation is needed for family members who provide care and respite programs should be available to provide temporary relief.
- 4) A universal health-care system is required to cover the costs of disability. There should not be any restrictions based on being status, non-status, on- or off-reserve.
- 5) Funding disputes based on political jurisdictional issues should be resolved, so that First Nations with disabilities can get the services they require.
- 6) Funding for training programs and education is required to assist Aboriginal people in developing the skills necessary to compete in the labour market which would aid in their ability to become self-sufficient and independent.
- 7) Employment Equity programs need to be enforced to ensure the hiring of Aboriginal people with disabilities.
- 8) Culturally sensitive programs are required to meet the needs of Aboriginal people with disabilities. Trained Aboriginal people are required to deliver these programs.
- 9) Aboriginal people with disabilities need to be involved in the development and delivery of programs.
- 10) An Aboriginal transportation system should be incorporated into the city. Considering the number of Aboriginal people with disabilities requiring means of transportation, the various bands should combine funding and purchase special buses.
- 11) Mechanisms are required to promote these recommendations and ensure that change is created.

CONCLUSIONS

This exploratory study utilized a qualitative analysis of four circle sessions with First Nations persons with disabilities. The research was designed to explore the issue of independent living and potential barriers as it related to Aboriginal people with disabilities living in the urban community. Not only has this study affirmed a number of issues previously addressed in the limited research on Aboriginal people with disabilities, it also has

exemplified the benefits of involving Aboriginal people in developing an understanding of issues that affect them. Their participation created a realistic personal account of the struggles many Aboriginal people with disabilities have to face in a society where oppression and racism continue. It also created a realistic personal account of how they are striving to overcome the obstacles placed in front of them.

In reviewing the literature and the findings, it is clear that Aboriginal people with disabilities encounter numerous barriers in their daily living. These barriers, many of which have been long-standing and socially ingrained, continue to keep the population with disabilities marginalized and isolated from the rest of society. Throughout history, Aboriginal people and people with disabilities have had limited access to resources and services which results in their exclusion from full participation in community living. Restricted or limited access has contributed to the high unemployment rates, low educational attainment, poor health, poverty, and high rate of disabilities.

Persons with disabilities have been forced to become long-term recipients of a program under social assistance. With its social stigma, "welfare" has become a way of life for many Aboriginal people with disabilities and, without the means for change, they are suffering in poverty. First Nations persons with disabilities face a dual dilemma in trying to break the cycle of deprivation. They may choose to remain on-reserve with limited resources, services and opportunities, but, where they will have their culture, family and community, or they may choose to move to urban centres in the quest for an enhanced quality of life and provision of services but in so doing, lose their connectedness to their supports, cultural traditions and identity. Unfortunately, widespread barriers restrict access to resources, economic opportunity and social integration. They face the double and interacting discrimination of being an Aboriginal person and a person with disabilities. Consequently, the attempt to achieve independent living is often blocked.

Clearly, it is through concrete and realistic steps that the numerous barriers facing First Nations persons with disabilities can be overcome, and their aspirations for participation in their communities attained. Aboriginal people with disabilities are seeking an improved quality of life, a life with meaning and joy, within the confines of their disabilities. They are entitled to benefits and services provided to mainstream Canadians. The courageous participants in this study want their voices to be heard. They do not feel their

disability is a "gift from the Creator"; instead, they want to surmount the barriers to obtain greater social inclusion, and a full and rewarding life.

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Engaging Numbers: Developing Health Indicators that Matter for First Nations and Inuit People

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Abstract

This paper addresses citizen participation in the development of community-level health and capacity indicators with a specific focus on processes that can be used to engage community members in indicator development. It is based on work that the authors completed with the Inuit Tapiriit Kanatami (ITK) in 2002 and work they have been conducting in partnership with the Prince Albert Grand Council (PAGC) and Athabasca Health Authority (AHA) in northern Saskatchewan. The latter project developed tools for First Nations health organizations to assess the impacts of their health and social service programs on community wellness and capacity. The project included a critical review of existing community-level population health indicators and indicator frameworks, the identification of gaps in the literature related to culturally appropriate community health indicators, and the utilization of a process by which these indicators might be implemented and tracked by First Nations health organizations at the community level.

In addition to the results of our work to date, we highlight some of the literature that specifically addresses Aboriginal conceptions of community health and community capacity along with an assessment of gaps in the literature in the context of culturally appropriate indicators. We conclude by discussing the processes that we have used with Inuit health groups and community-based First Nations health organizations in identifying culturally appropriate and relevant community health and capacity indicators.

Key Words

Community health, community capacity, population health indicators, First Nations, Inuit

INTRODUCTION

Numerous population health indicator templates or frameworks exist,¹ and work towards achieving a consensus on the most important indicators continues. Such frameworks are helpful tools both for conveying in simple ways the complexity of population health determinants and their inter-relationships, and for organizing the selection of indicators. We are unaware of any template or framework that incorporates Aboriginal community concerns, and know of only one general framework based upon the Medicine Wheel, which we discuss later in this paper. Developing culturally relevant population health frameworks is as important as engaging community members in identifying specific indicators; not doing so risks a disempowering

imposition of “expert” over “lay” knowledge and a failure of community stakeholders to use (analyze, interpret, act upon) the information that is gathered.

We begin by providing a brief overview of population health and community capacity indicators, including an argument for the importance of the availability and accessibility of these indicators at the community level. We provide a brief review of literature and results from other studies that discuss the development of Aboriginal frameworks and indicators to measure community health and capacity. We conclude by presenting the processes we used in two projects in order to highlight the importance of citizen involvement in developing indicators that are appropriate and meaningful in the context of specific communities. While the content of the indicators is very important, we argue

that the process by which these indicators are developed is equally important.

Population health indicators: a brief overview

Population health indicators are a subset of social indicators. Social indicators arose as an area of conceptual development in the 1970s in response to the failure of conventional economic measures (such as gross national product) to capture the factors that many people believed were important to their quality of life. They re-emerged in public, professional and research discourse in 1990s, as the push for evidence-based policy-making intersected with resurgent social movements and the rise of indigenous self-rule that called into question what type of “evidence” was important to collect, and for whose use.

Population health indicators measure the health of groups of people who share common geographic or political boundaries (i.e., communities, nations) or groups of people who share common characteristics (i.e., ethnicity, gender, age). They also measure health-determining social, economic and environmental conditions, and the equity (fairness) in peoples’ exposure or access to these conditions. Population health as a concept draws attention to health determinants that affect people as groups, rather than as individuals. Teaching someone to eat more nutritiously is an individual health issue. Ensuring that all people have access to nutritious food (its availability, its cost, its cultural appropriateness) is a population health issue. Population health indicators, in turn, are measurement systems used to monitor health and health-determining conditions at different political levels (i.e., international, national, regional, community), with the intent of informing how these conditions should be changed and identifying possible interventions.² While many population health indicators are collected at or available for larger geographic settings, it is becoming increasingly important for such indicators to be available at and/or collected from local communities, the level at which people live, work and play, and interact with services and service providers.

Population health indicators have several important uses: as benchmarks to track health in communities, as a communication tool in communities, as information for developing and monitoring programs, and, at a national level, as a means to advocate for funding for specific programs and policies.³ These uses, and their importance, are not simply academic; the Aboriginal groups with whom we have worked—the ITK and the PAGC—also spoke to the importance of having comparable and culturally relevant population health data

for their communities.

There is a caveat to the use of such indicators for program evaluation purposes. Causal links between population health outcomes, and health and human services programs, are hard to establish for well-known methodological reasons (i.e., confounding variables, lack of controls, lag time). Service providers, however, can develop evidence-based arguments for how or why they, and community members, think their programs or other interventions are making some positive contribution towards population health outcomes.

When applied at the community level, indicators should be designed, developed and researched by the community itself to coincide with the community’s goals, visions or desired visions of a healthy community.⁴ Using only “one-size-fits all” indicators is not realistic at the community level; the contextual dependence of relationships can have characteristics unique to each local community.⁵ This does not mean that local population health indicators will vary completely from place to place. Comparability between communities, as well as within the same community over time, affords important learning opportunities and is an element in gaining political attention to what changes in the indicators might mean.⁶ A core set of comparable indicators is therefore necessary and useful. Defining the content of this core set, however, needs to involve a wide representation of community stakeholders if it is to generate “ownership” and subsequent use by these groups. More importantly, the core set needs to allow variations (deletions, additions) that attest to community interests. This is particularly important in cross-cultural contexts, such as we encountered in working with diverse Aboriginal organizations, where the values, meanings and even existing selections of population health indicators are based on Western research and cultural assumptions. Another important point is that health indicators provide information, but not knowledge. Only when this information is discussed amongst and interpreted by community members (“What do the changes in these indicators mean about our health or well-being? What do we think is causing them?”) does it become useful knowledge that a community can use to improve its health, and that of future generations.

Community capacity indicators: concepts and domains

An increasing focus for health and human services, especially in Aboriginal communities, is tracking change in community capacities, and how

services can further build (develop) these capacities further. Hawe, Noort, King, and Jordens (1997)⁷ reviewed the popular health promotion literature to determine how capacity building was defined and conceptualized by health promotion researchers and practitioners. They found that capacity building was used in at least three different ways: health infrastructure and service development, program maintenance and sustainability, and problem-solving capability of communities and organizations.

The term “community capacity building” describes a wide range of health promotion strategies (i.e., community development, community empowerment, international aid and development) aimed at improving a community’s ability to improve and maintain its health.⁸ It is generically defined as a community group’s ability to define, assess, analyze, and act on health (or any other) concerns of importance to its members.⁹ Community capacity-building strategies involve dynamic social, resource and organizational relationships between individuals/groups, health and human service practitioners and service-providing organizations.¹⁰ In sum, community capacity building is a process of working with community members (usually organized into groups) to determine its needs and strengths, and to develop ways of using those strengths to meet those needs.¹¹ There are three roles for health and human services in this “working” relationship:

1. first, to facilitate the process by negotiating with the community the name and nature of the issues to be addressed,¹²
2. second, to help the community identify key capacities it wishes to improve in order to address these issues, and
3. third, to examine how health and human services, in their activities and programs, can play a role in supporting new actions on community issues, and enhancing desired community capacities.

With respect to the role of negotiating the issues to be addressed, the challenge for service providers is to accept that “expert” and “lay” knowledge systems often differ and are both important in a dialogue leading to identification of key community health issues based, in part, on information provided by local population health indicators. Moreover, community participation in programs and activities, and program sustainability, both increase to the extent the programs and activities are based on community-identified priorities, informed by

but never imposed upon by outside “expert” knowledge systems.¹³

With respect to the role of working with the community to address key capacities, there are several research-based models of community capacity, its measurement and how programs can contribute to its enhancement.¹⁴ These models identify key elements (or “domains”) of community capacity with detailed community capacity assessment questions under each domain. To date, Laverack’s¹⁵ community capacity model represents the most generic community capacity domains: (1) community participation; (2) local leadership; (3) empowering organizational structures; (4) problem assessment skills; (5) problem analysis skills; (6) resource mobilization; (7) links to other groups/communities; (8) equitable relationships, outside agents; and (9) community control over programs. While these domains already have a fair degree of cross-cultural generalizability, and some have been used with First Nations communities, experience in their development and use emphasizes the importance of a community undertaking its own identification of capacity domains.¹⁶ As with the meanings and potential indicators of local population health, the meanings and potential indicators of community capacity need cultural specificity if they are to be useful to, and used by, community members or health and human service providers. But also, as with population health indicators, there should be some core set of capacity domains allowing inter-community comparisons, as well as community comparisons over time. Several developers of community capacity frameworks recommend a “workshop” approach in which generic domains are presented, discussed, deleted, amended, or added to by community stakeholders.¹⁷

With respect to examining new actions that can be supported by health and human services, once the community capacity domains have been verified and/or amended by community members, they form a “parallel track” to regular health and human service programs. A new question arises: How do the programs contribute to improvements in community capacity domains identified by staff and community members as being important for community health?

Aboriginal population health and community capacity frameworks and indicators

We have discussed population health and community capacity indicators with only minimal reference to how such indicators can be made culturally relevant to Aboriginal groups. Our work with the PAGC

and the ITK, to date, strongly argues for population health frameworks that embody cultural symbols or schemata with which First Nations and Inuit people can readily identify, and with indicators that reflect health concerns that may have specific cultural meanings. In this section we review current Aboriginal population health frameworks and a sample of health indicator lists, and comment on issues associated with future development.

Population health frameworks

The Medicine Wheel represents Aboriginal health as a holistic life-view consisting of four dimensions—mental, emotional, physical, and spiritual. Leech, Lickers and Haas (2002)¹⁸ have developed a contextually and culturally sensitive framework for the assessment of Aboriginal health indicators based on the Medicine Wheel. Their “community life indicators wheel” is divided both vertically and horizontally. The right vertical half of the wheel represents the *spiritual* side of the model, whereas the left side represents the *corporal/physical world*. Divided horizontally, the upper half of the model represents the *intellectual* aspect of community while the lower half represents the *visceral* or bodily aspects of the community. Indicators have been suggested for each of the eight dimensions, or domains, of community life. Each indicator may be a partial measure of the “health” of the community, but it is the more subjective evaluation of the balance between the different dimensions, partly revealed by changes in the indicators, that is more important.

We were unable to locate any Inuit health frameworks. Our workshop with members of the ITK Inuit Health Technical Working Group, instead, presented two possible frameworks, both of them derived mostly from Western-based research but also “field-tested” in other cultural settings. The first model organized elements contributing to health into three overlapping circles, creating six different categories or domains (see Figure 1). This first model was used in 1999 to identify a short-list of community-level population health indicators.¹⁹ Members of the Inuit Health Technical Working Group and others, during their later interviews, reviewed a list of these indicators. The second model (see Figure 2) was a series of interconnected boxes that linked different types of risk conditions and risk factors to health outcomes.²⁰

Interview participants commented on the type of framework they preferred, specific aspects of each, frameworks in general, and indicators associated with the

Figure 1. The circle framework for population health indicators (from Hancock, Labonte, and Edwards 2000)

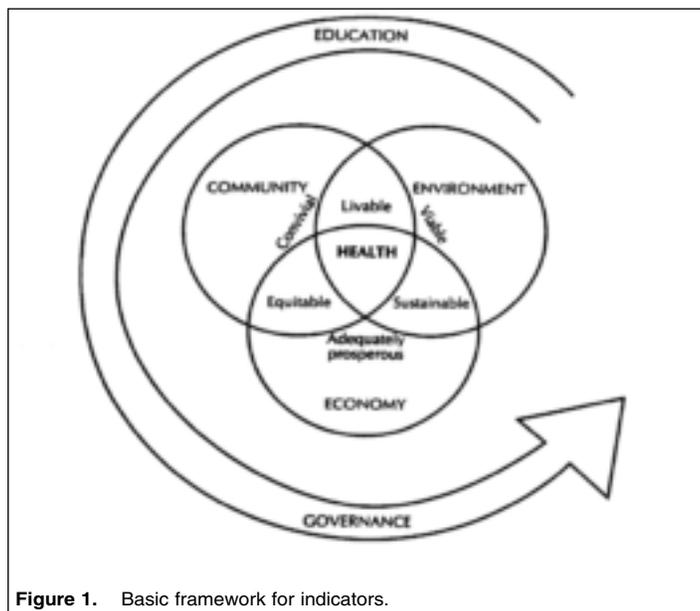


Figure 1. Basic framework for indicators.

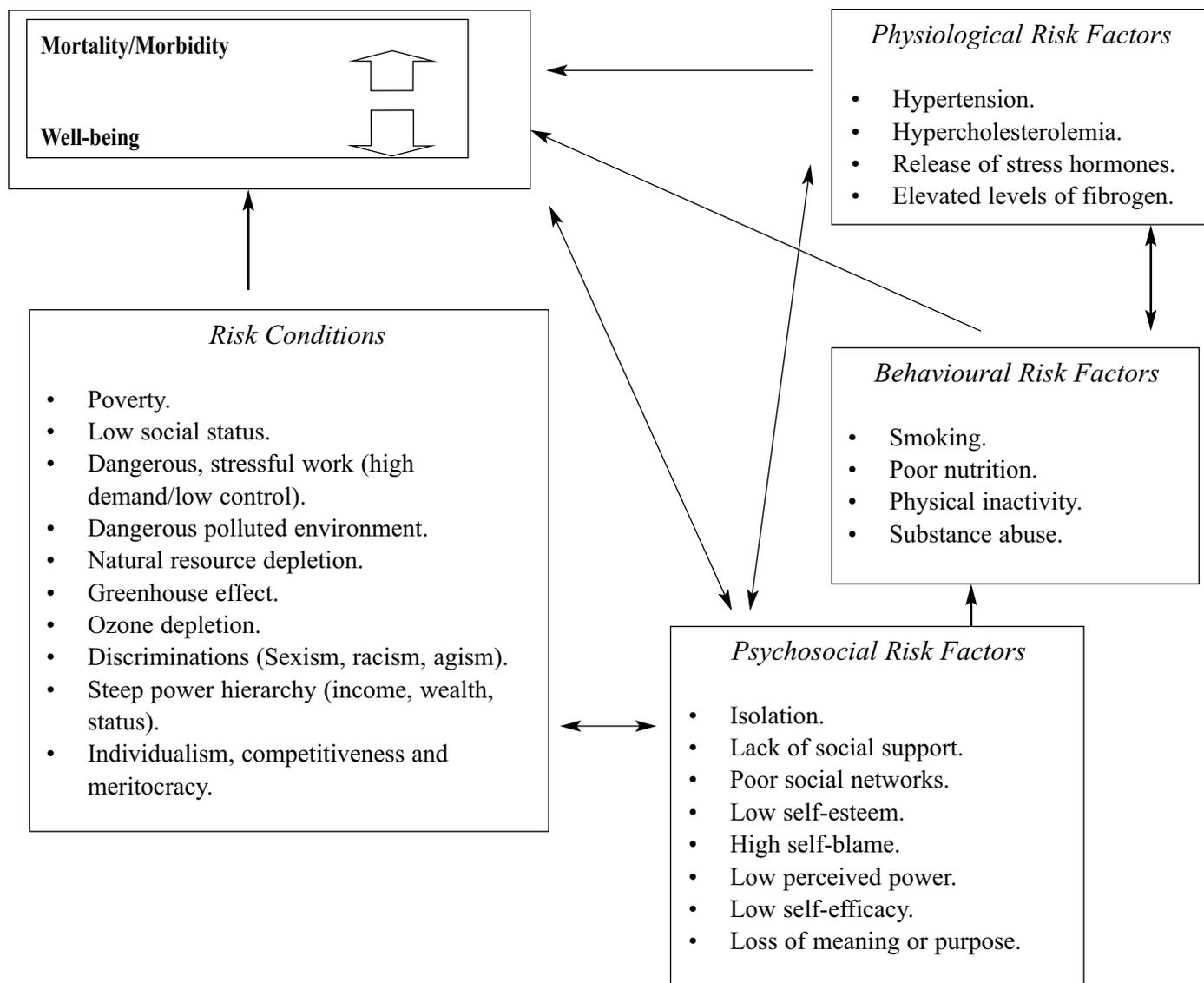
frameworks. The strength of the linear/box model was in its simplicity and the way it identified how different problems related to each other. This simplicity was also the weakness of the model; it was too linear and negative, and would not fit in well with Inuit culture, which valued positive, or critical, social conversation. Most people preferred the circles model as being more representative of the holistic view of health that exists in the North. One suggestion was to re-configure the model into an Inuit visual symbol; much of the terminology in the original model would also have to be changed to reflect Inuit cultural meanings.

Population health indicators

Health indicator projects have primarily stemmed from the need of individuals, communities, health administrators, health organizations, health advocacy groups, and government to develop meaningful measures to report on health and health services.²¹ Many indicator projects have been initiated in Canada and elsewhere; few, however, have focused on community participation within Aboriginal communities in the development of indicators or indicator frameworks that are culturally relevant and community (context) sensitive.

In 2000, the Health Transition Fund, an initiative of Health Canada, commissioned an evaluation of health indicator data for the Inuit regions of Northern Canada. Using the recently developed health indicator guidelines from the Canadian Institute for Health Information

Figure 2. The box framework for population health indicators (from Labonte, 1998).



(CIHI), Archibald and Grey (2000)²² found there were large data gaps and questionable reliability of what was available (i.e., extrapolation of numbers, lack of precision, conflicting values for each region under study, etc.). Archibald and Grey concluded that more reliable Inuit health data was required to make comparisons across regions; however, they neglected to adopt a collaborative approach to indicator development with Inuit peoples. The indicators developed in this project focus primarily on measures of morbidity and mortality that are centred on the measure of pain and illness.²³ They do not measure the health of a community in terms of its positive aspects or strengths (capacities) that exist, or that may need enhancement.

Our preliminary work with the ITK highlighted the importance of cultural contexts in selecting and

interpreting indicators. While the persons we interviewed supported an amended version of the circles framework, they also commented freely on the need for indicators under different categories that reflected Inuit life. Examples included traditional food as part of a definition of economic health in the North, wildlife availability as a measure for the physical environment and traditional knowledge as an important marker of education and community well-being.²⁴

The Institute of the Environment at the University of Ottawa, produced a report²⁵ that summarizes a number of initiatives focused on culturally sensitive Aboriginal health indicators. All initiatives used the Medicine Wheel as their framework and used a collaborative approach in determining culturally sensitive health and social indicators. Specific project

examples incorporated individual, family and community wellness indicators while others combined community disease and community life indicators. These examples are useful; however, the authors reiterate that the development of community health indicators “will take time and careful consideration to get the appropriate set of indicators for each community. But they will emerge from the process in response to the specific community needs and priorities.”

Community capacity

Although there are relatively few literature sources that have incorporated Aboriginal peoples’ perceptions of community capacity, the Government of the Northwest Territories’ *Community Wellness Strategy* (1995)²⁶ is an exception. As a result of consultations with 50 community members to determine what made Aboriginal communities healthy, the Strategy identifies some views of Aboriginal people regarding the definition and process of capacity building. The focus of community wellness was based on four areas of change: prevention, healing and treatment; education and training; interagency collaboration; and community empowerment. Identified strategies related to these four areas emphasize the importance of traditional healing practices, the need to support education provided by and for Aboriginal people, and actions that support communities in identifying and meeting their own needs and priorities.

METHODS

Emergent health issues have often unfolded in a crisis atmosphere requiring a reactive and rapid deployment of resources, further facilitating direct (external) intervention and control in the delivery of services. At the same time, there is no question that self-determination and cultural revitalization are among the key forces driving health and healing in Canada’s First Nations²⁷ and Inuit communities. Recognizing, measuring and building on these and other capacities acknowledges that contemporary health issues in Aboriginal communities are located in long-term development issues with roots in a colonial past. The development of indicators and frameworks that pay attention to the important processes of self-determination and cultural revitalization, and the capacities associated with them, can help community members to determine their needs and strengths, and to develop ways of using those strengths to meet those needs.

Our capacity-building project with the PAGC and the AHA focused on working with the local band and community leadership to determine community-specific health and capacity domains as population health indicators that can be used to track the well-being of their member communities. This project relied on a diverse group of people (chiefs and council, health directors, PAGC and northern provincial communities, community-based health practitioners) to problem-solve and develop culturally sensitive and sustainable indicators that can monitor the health and capacity effects of programs delivered by communities to improve health conditions and quality of life. Our work with ITK summarizes what key informants and existing literature suggest to be culturally relevant local population health indicators. It also summarizes where and how Laverack’s model²⁸ of nine community capacity domains “line up” with these indicators, both with findings from Inuit-specific health research and with what published literature and key informants identify (in a very preliminary way) as important Inuit-specific cultural capacities.²⁹

ITK project

The research that we completed in 2002 with the ITK had four objectives: 1) to critically review community-level population health indicators and indicator frameworks; 2) to identify a potential short-list of culturally appropriate indicators for Inuit communities; 3) to outline a process by which these indicators might be tracked and utilized by Inuit health and human services at the community and territorial levels; and 4) to critically review community-level mental health indicators and indicator frameworks.

For the purposes of this article, we will discuss the process that was used to accomplish these objectives. An introduction to indicators and indicator frameworks was presented in a workshop format with members of the Inuit Health Technical Working Group. Workshop participants emphasized that much of the literature speaks to international or Canadian First Nations contexts that do not reflect the context of Inuit people. This underscored the importance of further exploring frameworks and indicators that include Inuit-specific understandings and measures of capacity.

The circle framework that was previously discussed was used as a discussion guide in the workshop and was selected by workshop participants as the most useful one upon which to structure some of the questions for the interview process. Points raised during the workshop discussion were used to apprise the key

informant interview schedule. Key informant interviews were conducted following the frameworks and indicators workshop. Not all interview participants were able to attend the workshop, so brief one-on-one sessions orienting individuals to the workshop materials were conducted prior to commencing the interview. The majority of key informant interviews were conducted in person in the two days following the workshop, and one telephone interview was conducted at a later date. The analysis focused on participant perspectives of the indicators presented in the workshop, and on the identification of potentially useful new indicators specific to Inuit contexts. Other aspects of the analysis included background information on participants, participant perceptions of current health and capacity issues, and various domains of health-determining conditions, appropriate frameworks, indicator use, and aspects of data quality that include current availability, limitations and appropriate collection strategies.

The outcome of these interviews has been a report³⁰ summarizing potential Inuit-specific indicators (and areas where new indicators might need to be created) that was then reviewed by the Inuit Health Technical Working Group. Table 1 provides a description of selected domains discussed in the key informant interviews along with examples of some identified areas on Inuit appropriate indicators that require further development.

This phase represents only a beginning to the process that is desired by members of the Inuit Health Technical Working Group. While they feel they have views and perspectives to offer on indicator development, they also emphasize that next steps in this process must involve feedback and participation from community members, particularly youth and elders.

The project on First Nations tools for program planning and evaluation

The project with the PAGC and the AHA in northern Saskatchewan was completed in several incremental and iterative phases to develop a relevant evaluative and planning framework, and culturally appropriate indicators of community health in each of nine research sites in northern Saskatchewan. Research methods included a qualitative analysis of secondary data sources (i.e., relevant program documentation and reports, and a review of the professional literature), interviews with PAGC managers responsible for second-level services, interviews with community-based health directors, and focus groups with key informants involved in the planning, management and delivery of health and social services at the community level.

We completed the first stages of the research to synthesize literature in this area and to develop logic models³¹ that map the health and social services in each

Table 1 . Selected domains and examples of identified issues requiring Inuit appropriate indicators

Domain	Description	Identified Issue (Example)
Sustainability	Our use of the land is such that the land will still be useful to future generations	Time spent on the land
Viability	The land, its plants and its animals are in good health and are not threatened with extinction or habitat loss	Disposal of toxic products
Community Caring	Our communities provide supports to people in need. People take care of each other	Family life indicators
Prosperity	Our communities generate enough wealth to take care of our needs	Non-income measures of wealth
Equity	Resources in our community are generated by our economic activities and are distributed in ways that more people think are fair	Community sharing

From Labonte, Abonyi, and Jeffery, 2002

community to account for cultural and geographic diversity. Common themes emerging from these logic models were then used to develop a generic framework that was reviewed by the health directors and managers responsible for community-based programs and services, and subsequently adapted to accommodate community-specific elements.

Following this, an initial framework identifying domains and areas requiring indicators for both community health and community capacity was developed through extensive interviews with health directors. The framework went through two further revisions by this group. The outcome of this project is a community “toolkit” that outlines the identified domains for community health, the definitions for each domain and issues identified within each, and a set of indicators for each domain. We are now working with some of the communities to identify the specific indicators of interest, the availability of appropriate data and approaches for collecting additional community-level information to address the key indicators.

CONCLUSION

We have had two experiences with developing culturally appropriate indicators of community health and wellness: one with an Inuit health organization and the other with First Nations health organizations. The value of community knowledge and wisdom and the processes by which this knowledge is incorporated into more meaningful measures of community health is an essential step in indicator development. As O’Neil and Blanchard suggest, “The approach of developing indicators at the community level calls for a strong respect for the community and its members. It requires seeing the world through the eyes of the people who live in the community and reporting it in their words.”³² This experience and the processes we used (and are using) raise a number of questions and issues about our involvement with developing culturally appropriate indicators. Important questions relate to the ability of university researchers to implement community-based research so that communities can have genuine control over the development of indicators that are most appropriate for their communities. Assuming that we can have a useful role in developing these indicators, the question arises as to where our involvement should end. In the case of our work with ITK, it ended at an early stage, owing primarily to our own constraints respecting the local knowledge and time required to work more fully

and respectfully with Inuit communities. Our work with the PAGC and AHA is more open-ended and will likely be determined by the extent to which local health and human service organizations feel more fully capable of continuing with the indicator work on which we are presently collaborating. In summary, we continue to struggle and commit ourselves to working in a way that is most respectful of community and cultural contexts, and that produce indicators that are most meaningful to community members in their goals of enhancing community wellness and capacity.

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