



Some signposts for medical and nursing educational policy formulation for aboriginal healthcare

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As part of a larger ethnographic inquiry designed to ascertain how the Cree communities of the James Bay in northern Quebec viewed, interpreted, and handled the growing incidence of diabetes, this study explored the perceptions, knowledge, and experiences of health professionals serving aboriginal clientele in connection with diabetes. Qualitative data were gathered through in-depth interviews with 28 health professionals. Findings indicate that health professional perceptions of lifestyle are generated from within a nonaboriginal context and that knowledge and understanding of diabetes are rooted within patterns of health practices attributed to individual behaviour. The study concludes that trends towards individualizing the incidences and prevalence of diabetes obfuscate the socioeconomic processes affecting Cree people.

Introduction

There is an emerging recognition that existing preventive measures and some treatments in response to the growing incidence and prevalence of diabetes in North American aboriginal communities have not been as effective as in nonaboriginal populations. The implication is that forms of health professional education and practices seen as effective with nonaboriginal clientele may not be suitable for the particular cultural context that constitutes these communities.

This viewpoint is supported by growing evidence in the literature which suggests that North American health professional education programs rarely include initiatives in cross-cultural education. Moreover, specific structural components in cultural awareness and culturally relevant knowledge are frequently absent in health professional education (Marciniak, 1990; Masi, 1993; Moffic, Kendrick, Lomax, & Reid, 1987). While many Canadian colleges do offer instruction on consciousness raising and cultural sensitivity, there has been no mandate for this type of learning activity (Health and Welfare Canada, 1988). Provision, in other words, is often ad hoc and uneven.

Where education is provided, however, curricula rely upon and are informed by conventional conceptions of health and illness. More broadly, frameworks for healthcare have relied on the biomedical model (Lock & Gordon, 1988) and its status as the dominant model has remained virtually unchallenged (Wright & Treacher, 1982). It has been vigorously argued that formal health knowledge has assured an increasingly scientific and technical status (Kleinman, 1988; Wright & Treacher, 1982) and defines health and illness within strictly physical parameters (Helman, 1990). At the same time, there is a substantial body of literature which argues that the experience of various cultural communities facing health and treatment in North American society creates tremendous stress on patients and their families because treatment and planning is often not in agreement with traditional understandings of healthcare (Stephenson, 1991; Hopkins, Kavanagh, & Kennedy, 1992).

Common barriers to healthcare in cross-cultural situations have been cited as differing perceptions of pain and suffering; contrasting views surrounding treatment modalities; language misunderstanding and different interpretations surrounding meanings attributed to illness (Boston, 1994; Kleinman, 1988; Molzahn & Northcott, 1989; Stephenson, 1991). All of these studies reveal that subjective views of treatment and healthcare and the cultural context of illness need to be recognized if healthcare and treatment are to be culturally relevant. The most consistent argument for resolving misinterpretations of health and illness has been to treat seriously the cultural knowledge and personal health beliefs of patients and their families (Helman, 1990). For example, recent studies on diabetes prevalence among aboriginal people have begun to focus on lifestyle patterns (e.g., return to the bush) and their effect on diabetes control (Robinson, Gebre, Pickering, Petawabano, Superville, & Lavallée, 1995). Although there have been numerous survey-type studies which have attempted to explore and connect diabetes with particular cultural trends (high junk-food consumption, stress at work, and sedentary domestic habits) in both metropolitan and aboriginal populations, few studies have used a qualitative approach to investigate the perception and lay understanding of diabetes, or the social and cultural meanings of the disease, within aboriginal communities (Garro, 1994; Travers, 1995). Similarly, little attention has been given to the way in which diabetic health services and health professionals' practices are organized in relation to the cultural understandings and practices of patients and their families.

Using findings from a study conducted between September 1995 and December 1996, this paper reports on the experiences of healthcare professionals serving aboriginal clientele among the nine James Bay Cree communities of northern Quebec (Boston, Jordan, MacNamara & Kozolanka, 1996). The purpose of the study was to determine how healthcare professionals (HCPs) were responding to the growing incidence and prevalence of non-insulin dependent diabetes mellitus (NIDDM or "type II") among the James Bay Cree.

As we show, our research suggests that the relative ineffectiveness of the healthcare system to stem the growth of diabetes among the James Bay Cree can be partly attributed to the character and content of HCP education. This education, we argue, is generated from within an institutional context that takes little account of the very different experiences and cultural meanings which aboriginal communities bring to health and social problems confronting them. Consequently, we argue for the adoption of health professional education programs and policies that are sensitive to the cultural contexts in which they are to be implemented.

Background to the study

Until the construction of hydroelectric projects from 1971 by the Quebec government, the James Bay Cree of northern Quebec continued to lead a traditional lifestyle organized around hunting, trapping, and fishing. With the construction of the hydroelectric dams, the building of a road into their territories, and other economic development (e. g., mining and forestry), the Cree began to feel that their lands and way of life were under threat. To prevent further development without their consent, the Grand Council of the Crees mounted a series of court challenges against the Province of Quebec and the Government of Canada from which the James Bay and Northern Quebec Agreement (JBNQA) emerged and was signed in 1975. The JBNQA effectively allowed the continued economic development of the James Bay in exchange for specific rights and provisions allowed to the Cree concerning: specified land rights over hunting, fishing, and trapping; provisions for local and regional government authority; the establishment of a native-controlled health and education authority; the local administration of policing and justice; and a special native economic development regime for the region. These provisions apply to the nine Cree communities of Mitissini, Waswanipi, Eastmain, Wemindji, Waskaganish, Chisasibi, Nemaska, Whapmagoostui, and Oujé-Bougoumou.

The signing of the JBNQA is generally recognized to have had profound implications for the Cree and their traditional way of life. The flooding of vast areas for hydro development not only displaced many Cree from land they had settled, but also compromised their access to traditional hunting, trapping, and fishing grounds and thus, to sources of food highly valued by them. More broadly the economic development generated by the JBNQA has gradually imposed a “southern” way of life on the Cree. Modern housing, skidoos, television, domestic appliances, and store-bought food have all contributed to a shift away from life on the land. While they recognize that the transformations flowing from the JBNQA have brought many material benefits, they are gradually becoming aware of the costs of such development.

One of these “costs” has been the dramatic rise in the number of Cree developing diabetes mellitus that has coincided with the development of the James Bay since the early 1970s. As of February 1997, statistics released by the Cree Board of Health and Social Services of James Bay (CBHSSJB) show that there were 607 cases or 8% of the population 15 years and over who were diagnosed with diabetes. However, the CBHSSJB recognizes that these figures probably underestimate the true extent of the disease, as many Cree have no obvious symptoms and thus may remain undiagnosed for years. Most worrying of all, the statistics show that not only is the the number of Cree with diabetes increasing but “many young people are being diagnosed with diabetes” (CBHSSJB, 1997).

Despite the determination of the CBHSSJB to prevent the growth of diabetes among the Cree, there has also been an emerging recognition that existing preventive measures and some treatments have not been as effective as in the south. The implication is that forms of healthcare and education proven in the south may not be suitable for the particular cultural context that constitutes the Cree communities of the James Bay. It was for this reason that the CBHSSJB commissioned our study to investigate and explore how forms of healthcare provision aimed at the prevention of diabetes can be constructed by the CBHSSJB using Cree understandings and experience of the disease.

The study: Methods of data collection and analysis

The findings of this paper are based on data we gathered on non-native HCPs working in the Cree communities of the James Bay. The data formed part of a larger study concerned with investigating how Cree knowledge, understanding, and experience of diabetes might inform and shape the construction of policy and program provision concerning treatment and prevention of the disease (Boston et al., 1996). Consequently, although the paper's findings are framed by this larger study, our primary concern will be to explore how predominantly white, non-native HCPs interacted with the Cree communities over prevention and treatment of diabetes. Before we commence our analysis of the HCP data, therefore, it is necessary to outline briefly the two interrelated strands of the broader study we refer to.

The first strand or component of the study focused on exploring how diabetes was understood and experienced by Cree diabetics, their families, relatives, and friends within the nine communities of the James Bay. For this part of the study the CBHSSJB allowed us to recruit and prepare all nine of its Cree Community Health Representatives (CHRs) to collect qualitative data on diabetics within their respective communities. With the CHRs' consent, an education program was organized through a series of workshops between September 1995 and February 1996 where we introduced them to the basic principles and practices of interviewing, writing fieldnotes, analysing qualitative data, and ethical issues. Throughout these workshops we encouraged the CHRs to draw upon their own professional and personal knowledge of Cree culture and society to inform and develop the research design which we had initially brought to them. In this respect the workshops provided a forum for the mutual exchange of ideas, knowledge, understanding, and skills that allowed the emergence of a Cree standpoint on issues pertaining to diabetes.

Over the 7 months of the study the CHRs conducted 45 interviews with Cree diabetics. These were tape recorded, translated (from Cree) and transcribed for later analysis. Interview questions were structured around four key themes that emerged from discussions with the CHRs. These focused on: Cree perceptions and understanding of diabetes; traditional/community approaches to healing and diabetes; patients' experiences of treatment and more generally the healthcare system; the social and psychological consequences of developing the disease. As the research progressed the CHRs also began to ask questions concerning the impact of economic development (particularly the Hydro-Quebec dams) in the James Bay as respondents frequently related this to the emergence and spread of diabetes in their communities. A fifth theme, focusing on traditional Cree methods of healing and spirituality, was not pursued at the request of the CHRs. One of them in particular (a Cree Shaman) argued that these were sacred to the Cree and could not be shared with the uninitiated and particularly outsiders. We respected these views. In a series of tape-recorded roundtable discussions and individual interviews at workshops the CHRs also discussed with us their own experiences and observations of work with diabetics within their respective clinics which were added to the data archive.

The second strand of the research – which we report on in this paper – focused on researching the understandings and views of HCPs regarding the spread of diabetes among the Cree communities of the James Bay. The designation HCP refers to a broad range of healthcare workers including physicians, nurses, nutritionists, dentists, and social workers. Unlike the Cree CHRs, this group was predominantly white and non-native (one nurse was Cree). The purpose of this component of the study was to

ascertain not only how HCPs were actually responding to the growing incidence and prevalence of diabetes among the Cree, but how their work in this area might be improved and supported through both formal and informal mechanisms within and outside the healthcare system. In particular, we wanted to identify what HCPs saw as barriers to the effectiveness of their existing work practices in relation to diabetes and through what kinds of provision these might be overcome.

Data for this strand of the study were primarily generated from extended interviews we conducted with HCPs working in the nine Cree communities. Twenty-eight healthcare professionals were interviewed from medicine, nursing, dentistry, social work, dietetics, and human resources. While a quarter of those we talked to had between 2 and 5 years' experience working within the James Bay, the majority had from 5 to 22 years. With the approval of the CBHSSJB we approached and gained the consent of each respondent for participation in the study. All HCPs were briefed on the design, aims, and purposes of the research before commencing interviews and asked to sign a document expressing their willingness to participate in the study. This "consent form" assured them of confidentiality and anonymity in any document or publication arising from the research.

All interviews were conducted on-site in clinics, hospitals, and other workplaces in the James Bay over the duration of the study. Interviews were administered with an interview guideline that had been developed in consultation with HCPs who had working experience in the James Bay and some knowledge of diabetes as it affected aboriginal populations. Questions focused on aspects of health professionals' working lives and practices, including: previous and current education on diabetes; their beliefs and understanding of diabetes; prevention of diabetes; what they perceived to be clinical strengths and weaknesses in the treatment of diabetes; their views on existing treatment programs (in the south and James Bay); perceptions of relationships with Cree patients and families; specific assessment and intervention patterns; and the day-to-day management of diabetics. Observation of a three-day training module for CHRs on diabetes taught by HCPs (a nurse, two dietitians and a physician) as well as attendance at several seminars and lectures concerned with diabetic treatment and care also formed a significant element of our data-gathering procedures. We also collected and referred to a broad range of CBHSSJB research, policy documents, and other materials, such as the Cree weekly *The Nation*, to inform our work.

Analysis of data generated from both the Cree and HCP strands of the study was conducted simultaneously. This allowed the development of a constant comparison method that enabled us to make connections and draw inferences from the findings of both components of the research. By constructing a set of topics (which underwent continual development) we organized and placed data into these for retrieval as the study progressed. From the initial topics, a set of broader themes and categories was devised. Each theme usually incorporated a number of categories that reflected health professionals' concerns, understanding, experience, and knowledge in response to the growing incidence and prevalence of diabetes and the barriers they perceived to their existing work practices. Thus the aim of analysis was not to tabulate categories, but to examine recurrent patterns and processes in health professionals' work practices. The data contained within these themes and categories were then used as a basis from which to construct the study's findings.

With the findings from the Cree strand of the study we were then able to produce a draft report which was circulated to all CHRs, HCPs and members of the CBHSSJB for comment, observations, and other feedback. There were varied responses to the study's

findings, ranging from total disagreement with the perceived problems of communication by some HCPs, to the ready acknowledgment by others that the study had revealed some important lessons to be learned in both clinical practice and the ways that diabetes education was currently disseminated. In general the CHRs and those Cree representatives of the Cree Board of Health concurred with the findings and resolved to advocate for change in current policy-making processes concerning the development of diabetes programs and services. This process not only allowed us to engage participants in a constructive dialogue over the content and major findings of our study, but also served as a critical validity check. After we had received comments on the draft report and made revisions, a final report was submitted and accepted by the CBHSSJB (Bobbish-Rondeau et al., 1996). With a foreword by the CEO of the Cree Board of Health (a Cree chief), over 200 copies of this report have now been circulated within the nine Cree communities of the James Bay as a means to stimulate local discussion, debate, and action on how to draw upon Cree knowledge and experience in the fight against diabetes. In what follows we report on findings derived from the healthcare professional component of the study to illuminate what problems and possibilities they actually encountered and envisaged in the development of such a strategy.

Healthcare professionals and diabetes

For the purposes of consistency and clarity in this paper, we use the term “Healthcare Professional” (HCP) to describe the people we interviewed who have as their vocation some responsibility for healthcare provision. The term includes nurses, nutritionists, and others with professional interests in the field such as dentists, social service providers, and supervisors of those providing healthcare services, in addition to physicians (in direct service working full time or as temporary replacements, as well as physicians providing inservice and support, back-up and training). It is important to note that only one of the HCPs we interviewed was of aboriginal ancestry.

Professional orientation and education

One of the major findings of our research was that the majority of HCPs had received limited education on the clinical management of diabetes mellitus within different cultural contexts. HCPs felt that not only did their medical education provide them with an inadequate medical understanding of the nature of diabetes, but also that it failed to prepare them for working with patients drawn from aboriginal communities in the north. This judgement was shared by all but two of the HCPs we interviewed, irrespective of whether their education had taken place within a university, CEGEP/ community college, or other accredited institution. As one HCP described it:

You have the basics and then you just develop your own sense as you're here [in the community]. You know, how to treat the people and more practical things... and then you realize that there are some things in the education that are different. So when you get to diabetes and very quickly realize that there are people who are way out of control with diabetes. All we had really learned was that you start with oral pills, and if they don't work you go to insulin, so I guess I would have started doing that, except that I saw so many people that were

already on insulin and were way out of control. And then I said, “Okay, well we’ll increase the insulin,” but when I would look up in the chart it had been happening for years and it was still way out of control, so you start thinking maybe that wasn’t the solution. And in all the lectures we had about diabetes they would always start by saying, “Okay, for diabetes, first time treatment is exercise and diet and you should give it at least a six month trial.” After that you go to oral hypoglycaemics and then the next forty minutes was about the pills. That was all we got about it basically. We got nutrition in medical school, we got biochemistry, there was nothing practical.

Many HCPs we interviewed indicated that the only way they could compensate for this shortcoming in their education was to acquire knowledge and skills on the job as part of their everyday work routines within the James Bay Cree communities where they were employed. As one HCP succinctly put it, “you just had to learn on the spot to complement what you learned.” Two notable exceptions to this pattern were HCPs whose speciality was in nutrition. Both indicated that cultural issues were an integral part of their curriculum and formal professional education and that this had helped them in their work with the Cree.

As the fieldwork progressed we began to ask our informants about what kind of preparation and orientation they received when they first came to the north. The majority of reports revealed that the most common form of orientation was “learn as-you-go:”

Orientation? We have nobody to orient us within the Cree community when we come up. There was someone who did that years ago but on his free time... there’s not enough resources in the field here. I think everybody learns on their own by being involved in the community and doing things... it depends.

While most HCPs said they had received a certain amount of guidance from brochures published by the Cree Board of Health and Social Services of James Bay (CBHSSJB), they had mostly gained their knowledge of Cree culture, traditions, and customs through their own efforts and initiatives after arriving in the north. Thus, it seemed to us that HCPs experienced a double deficit as newcomers to the Cree communities of James Bay. First, their formal education did not sensitize them to the different ways in which aboriginal communities in the north understood and dealt with medical problems such as diabetes. That is, while the majority of HCPs claimed to be well versed in the medical/scientific causes and treatments of diabetes, they nevertheless expressed a concern that, by itself, this was inadequate in the context of the Cree communities of James Bay. Second, they felt that this deficiency in their education was further compounded by the absence of any formal mechanisms (e.g., an orientation day, seminars, talks etc.) for educating them about Cree culture on their arrival in James Bay. Providing HCPs with brochures, books, and other forms of printed material was useful but could not be a substitute for formal mechanisms of familiarizing them with Cree culture over a reasonable period of time.

The concept of “lifestyle”

We wanted to understand how HCPs perceived diabetes by asking them to describe for us how they saw and experienced it as part of their everyday healthcare practice. A common theme to emerge in their reports was that diabetes was largely a product of

what they termed “lifestyle.” How lifestyle was understood to be connected with diabetes by the majority of HCPs can be seen in the following interview extracts:

Basically it’s a lifestyle disease, not necessarily caused by lifestyle [but] worsened by lifestyle and culturally controlled by lifestyle. If someone has blood sugar that’s excessively high, if they would change features of their lifestyle, for example, doing considerably more physical activity, not driving to work and not driving every 15 feet, using axes instead of chainsaws. There’s all sorts of things, like making it a point to do physical activity and if they would alter their eating habits quite dramatically... and reduce their weight, they would either be a well-controlled diabetic or not one at all. It’s a lifestyle and social problem... most of the patients we see here are Type II and since a lot are overweight and not exercising a lot, I guess the huge transition they had to make was from being very active and eating a diet that was suited for that activity to all of a sudden now being almost completely inactive. Shopping at the “Northern” [a store] for food and just being in very stressful situations. There are a lot of social problems among the Cree which I’m sure does not add to people’s well-being. Following a healthy diet is not top of their things to do.

In other words, lifestyle referred to an interrelated group of everyday practices that predisposed Cree people to developing diabetes. These included lack of exercise, poor diet, putting on weight, stress, and a more sedentary mode of living. Other factors such as a suspected genetic predisposition to the disease were also raised. Understood outside of their relationship to the social, economic, and cultural changes brought about by the James Bay Agreement, these factors were commonly seen as arising out of the habits and choices that individual Cree made about their lives. That is, diabetes was perceived to be consequent upon individual behaviour that either caused or exacerbated the condition.

However, a smaller group of HCPs felt uneasy with this particular interpretation of lifestyle and its use in explaining the growing incidence of diabetes among the Cree. They argued that it tended not only to foster a mentality which “blamed the victim” but that it also failed to connect the growth of diabetes in the James Bay with the political, social, and economic forces that had brought “the dam” and other forms of economic development (e.g., mining and forestry) to the region. Understood this way it was not an individual’s lifestyle per se that caused diabetes, but “a change in lifestyle. Twenty years ago there was no diabetes. Since then there’s been changes... and now they have diabetes.” For example, one HCP with some considerable experience of working in the Cree communities of the James Bay said that “the James Bay Agreement [1975] has brought the road, television, telephone, cars, chainsaws, fridges, freezers and so on. It’s established economic relationships” that not only profoundly affected the everyday life of individual Cree, but undermined and reorganized the traditional social relations that constituted the Cree communities.

For this group, lifestyle was therefore not just a matter of individuals making ill-considered choices concerning personal behaviour over exercise or diet, it was also fundamentally shaped by political and socioeconomic forces that were redefining how the Cree were to live in the contemporary world.

While the effects of this “change in lifestyle” brought many benefits, it was also recognized that such change had brought subtle, but nevertheless profound, consequences for the way that the Cree had traditionally organized their lives. As one HCP observed, the tensions arising from this change process had filtered into the everyday

fabric of Cree culture. Recounting personal experience on monitoring blood sugar levels among Cree diabetics, she noted that:

We sometimes find that they get a little controlled and I don't know what happens and then they let it [blood sugar] out of control. It's like at Christmas time they go right out of control, because everybody eats so much. There's a lot of feasting going on at Christmas time. You always find the blood sugars going a little off ... when they stay in the community I find their sugars are not as controlled as if they're out in the bush and they're working and burning ... and if they're working hard, like they usually do ... it's always hard work when you live in the bush. You know, it's not flick the light on, or turn the stove on ... it's go and get the wood, cut it up ... carry the water. If this kind of thing is happening, then it's good. But if you're not going to change your lifestyle – your whole lifestyle – you're going to live on your traditional foods and stuff like this [and] you sit there and eat your mooseburger or whatever, or you've got rabbit and dumplings and sit there in front of the TV ... it's not going to work, eh?

Clearly, then, blood sugar levels were not regulated through sheer force of individual will but through complex social processes that depended upon whether patients were “in the community,” or “in the bush” – an observation that many other HCPs reported to us. That is, a traditional or a modern lifestyle appeared to either induce or mitigate against forms of behaviour that were conducive to the control of blood sugar levels and diabetes. This view was reinforced by another HCP, who also noted that as with blood sugar levels, diabetes could not be isolated as a medical problem from the culture in which it occurred:

You know, it [diabetes] involves the culture, the way people have learned to do things. Your lifestyle if you prefer. It's already a big problem with the Cree people and it's going to become more and more so ... because before they used to be in the bush, they had a hard life, but now they're in houses, it's overcrowded and they're not as active as before. It's like a change that has been sudden – but it's been slow too. When they were in the bush everything that they could eat was good. Here it's not true. They have to make different choices, so you know – I think it's a complex problem. You cannot just treat diabetes by saying “It's a sickness and this is the medication, this is the diet, this is the exercise.” You have to work absolutely with the culture and with the family ... the setting, the lifestyle.

Diabetes was, therefore, mediated by a complex array of cultural factors which were specific to the make-up of the Cree communities of the James Bay. Understood from this perspective and in the context of radical social change and transformation since the hydro developments of the 1970s, diabetes was seen as a “complex problem” which could not be reduced to individual behaviour or lifestyle alone. This way of reconceptualizing the links between diabetes and lifestyle has important implications. In particular, it recognizes that the relationship between individual behaviour and diabetes is not as straightforward as is often assumed in the prevalent conception of lifestyle. As the HCP notes above, diabetes is not a “sickness” that can simply be treated with “medication,” “diet,” and “exercise.” What also has to be taken account of is not only the particular cultural context of the Cree communities of the James Bay, but that these communities are still attempting to come to terms with fundamental change processes that have reorganized their relationship to one another and, most crucially, to that of the land and food supply. Understood in this wider context, the prevention and

treatment of diabetes implies that HCPs must “work absolutely with the culture and with the family... the setting, the lifestyle.” It strikes us that this particular concept of lifestyle would be the most useful in informing policies and programs aimed at diabetes prevention.

Food and diet

A recurring theme found throughout many of the HCPs' reports was concerned with the way in which food played such a central role in Cree social life. An example of this can be found in the following account:

Another problem is probably the role food plays in the Cree society. For instance, when you served by somebody, you must clean your plate, otherwise you're telling the other person you're not happy with the food you've been given. That's the protocol here, so that you can see if you go visit people in the evening, you end up piling on large amounts of calories just by conforming to the standard.

From the accounts of HCPs it became very apparent to us that diet and food were central to defining Cree culture and identity. They emphasized how food and the various rituals surrounding it acted as a focus for the transmission of traditional Cree customs and values which they had brought with them from the bush. In particular, there were frequently reported misunderstandings surrounding cultural beliefs and mores between the HCPs and the Cree community. From these reports it became clear that many communication barriers arose from the cross-cultural dynamics between Cree and HCPs. Participants' views on the meaning behind communal eating and its rituals were not well understood by the HCPs. Food, such as goose or goose fat, that is considered unhealthy by the health professionals, is perceived to be fundamentally beneficial and necessary for life by the Cree. For example, in early May of each year the Cree have a “goose break” where hunters go out to shoot geese with the aim of storing large quantities for year-round consumption. Goose is believed to be rich in nutrients and the fat from the goose is viewed as having a healing quality (Garro, 1994). This and other similar activities mark a tension between what is generally understood by Cree to be a previously “healthier” lifestyle of sharing food obtained through hunting and fishing and “southern” food obtained since the decline of “bush life” from stores.

Moreover, while “southern” diabetic teaching requires strict adherence to a “diabetic” diet for individuals, being polite and respectful to family and community means joining in the communal ritual of eating. To openly refuse food is to be disrespectful. From the point of view of community members, the act of refusing food is synonymous with the act of separating a Cree person from his/her family and community life – it imposes a form of individuation hitherto alien to Cree culture (Boston et al., 1997). While it is clear that the social dimensions of sharing food through custom or ritual are common to many cultures, food rituals within Cree life are inextricably interwoven within its traditional culture and system of beliefs. A recurring theme of life and health in native cultures is the circle. You are born into a “circle” of a family and a community that supports you and you, in turn, support it. Eating as a community activity is therefore a communal activity. Not being able to “share” in the social function or ritual then becomes a community problem, as well as a problem for the individual. Mintz's observation that “foods eaten have histories associated with the pasts of those who eat them [and] its consumption is always conditioned by meaning.

These meanings are symbolic, and communicated symbolically; they also have histories” is pertinent here (1996, p. 7). In relation to this, it is also worth mention that traditional/community approaches to healing and diabetes were perceived and conceptualized within the Cree perspective of healing and treatment modalities, even though Cree diabetics reported “following the teaching of the HCPs” (Boston et al., 1997).

This complex relationship to food was outlined for us by an HCP who was also a Cree. She remembered from her own childhood experience that animal fat was essential to a traditional Cree feast:

You have to remember though, that’s a very traditional thing [animal fat]. That’s the way they eat. To pass the... what was it – they used to do this, I remember when I was a kid – pass the fat of the animal, like the grease and everybody would take a little spoonful or a little gulp of it – and it’s like a – it was like a ritual for us. For example, we had a feast at my mother’s one time when I got to visit. This particular time I went to visit and my mum was cooking a goose. And my dad was sitting on the couch and my mum and I were preparing the table and all this goose fat was there. And I like the very bottom part, you know, where the crunchy pieces are... not the greasy part – I don’t like that. So I said to my mum, kind of like so my dad wouldn’t hear me, “Do you think we could trim this off? You know, scoop this up – this fat here?” Oh, my dad overheard and said something about he had feasted many a time... meaning that he’s always lived like this, he’s always feasted like this – it’s what you do!

Animal fat, in this instance goose fat, was therefore a key constituent of what her father considered “good” and nutritious food. Furthermore, it was a central component of a “feast,” a social occasion that brought immediate family, relatives, and friends together. It was part of the old ways of doing things. As her father exclaimed, it’s simply “what you do” if you are Cree. Our point is that the dietary habits and customs of the Cree are integral to the maintenance and reproduction of their culture and that this has to be taken into account in the formulation and creation of preventive measures for diabetes. We wish to emphasize here, as our findings suggest, that HCPs possess inadequate information concerning how traditional Cree foods can be incorporated within dietary regimes for diabetics. For example, there was some confusion over whether goose, bear, or beaver fat should be avoided in the same way that beef fat is by diabetics. Relatedly, some HCPs also expressed concern that to designate certain traditional foods (e.g., goose fat) as “unhealthy” for Cree diabetics was to stigmatize key components of Cree diet and culture.

Managing diabetes as one of many (social) problems

Diabetes was often referred to by HCPs as an issue that was intertwined with other medical and social problems. Some of these were outlined for us by one of the HCPs we interviewed:

As soon as they sit down, they want to talk to you. No matter what, how standard the problem may be that you’re seeing them for, no matter how simple it looks, it usually turns out to not be that. As soon as they sit down, “Oh, I’ve been in jail. I’ve been drinking,” so whatever else you thought you were going to do during the visit takes second place. You have to deal with that first. That’s what is contributing to their health problems too.

Another HCP encountered similar problems in attempting to reduce blood sugar levels among diabetics:

When I first came up we tried to figure out how to get their blood sugars down. We'd talk a bit about diet and how they should change, we'd put them on pills and they'd come back and we couldn't see any change. They just couldn't seem to get a handle on it [and] would feel guilty. I think if we understand they're people with so many other issues on their mind, they really didn't have time or energy to focus on what they were eating.

That is, following conventional medical wisdom, the control of diabetes requires both a specific kind of self-discipline and energy which, for a number of Cree confronting personal or family crises, is likely to be out of reach. HCPs reported a range of issues militating against their Cree patients maintaining a careful regime of medication, diet, and exercise. For example, several HCPs we interviewed emphasized that some of their patients were dealing with social problems which made it difficult for them to focus on controlling their diabetes. Because of the pressures and tensions that these events produced on family life it was often difficult, if not impossible, for diabetics to actively control their condition and complications arising from it, such as irregular blood sugar levels. While the HCPs we interviewed showed great sympathy for these problems, they nevertheless felt perplexed and a sense of impotence in treating diabetes under these circumstances. As one HCP put it:

I know that for the people at the clinic, it's really – you see these people every day, you see that there are problems every day. Sometimes we have to deal with social problems, psychiatry, emergencies, community health – you need answers. And to me, right now, I don't think that we give them answers... things to work with, concrete stuff, help... we do our best, but we're not good in everything.

Aside from a general desire to acquire more and better education on diabetes, its causes, symptoms, and complications, there was a strong belief among many of the HCPs we talked to that such education had to occur within a broader strategy that took into account the personal and social circumstances that their patients confronted. That is, without a broad understanding and sensitivity to the particular social problems that the Cree communities of James Bay face, healthcare and education aimed at diabetes would continue to be ineffective.

The invisible nature of diabetes

A number of reports from HCPs revealed an apparent ambivalence or reluctance on the part of many Cree with diabetes to accept treatment for their condition. This was interpreted as a form of complacency towards a disease that did not appear to present to individuals, at least in the short term, any serious complications. Thus, many of the HCPs we talked to observed that diabetes was difficult for the Cree to acknowledge because they “think as long as they walk, as long as they do what they do – they're not sick.” As one informant put it:

I think that diabetes is abstract for a lot of people not just Cree people you know. It's like...it's not concrete, it's not something you see the signs early on. So sometimes for them, it's just like – it doesn't make any sense, you know. Like, if they don't see – if you see a cut and you say “It's a cut” ... or ... you see there's an infection, you have to do soaking, you have to put antibiotic cream or you have

to take pills. It's concrete, they'll do it, because they can see. And after three days if it doesn't work they're going to come and say it doesn't work, okay? Or, if in three days it's gone, they know it worked ... but diabetes, it's hard for them to even get a grip on the fact that they actually have diabetes. So when you don't believe or you really don't see the effect ... it's hard to get it across.

As this HCP noted, this was not a problem specific to Cree diabetics but was also a common response of people in the south with non-insulin-dependent diabetes. We wanted to find out more about its invisible character and the ambivalence of the Cree toward treatment of the condition that our informants mentioned in their conversations with us. The Cree HCP who we referred to above – who had developed diabetes – made the following observations on this issue:

I had heard about it – it existed in the community and was on the increase but it really didn't affect me – until my own personal experience when my sugar went very high. It really affected me, it really affects me greatly – not just for myself, but for other people. I wanted to know and learn what it does and what happens when it goes on and the extremes that it can develop into and the kinds of problems a person can have. One of my aunts who has it ... she got really depressed a couple of years ago because of it you know, because she had a deep understanding of what it could do to you if you don't take the time to take care of yourself. You know, and she got very, very depressed ... and I remember personally, when I was told that I had it ... I got very upset and was in denial of it. And I told the doctor, "You know, I don't feel sick, I don't feel it, I don't feel it's there." But it's there. And I think what is so hard for people to grasp is that ... when you have it, it's so difficult ... because you don't feel sick. And I think that is what is so difficult ... because in the Cree culture, they need to feel, they need to see things in order to believe things, that they're there.

Overcoming the invisible nature of diabetes was therefore considered by HCPs to be one of the major obstacles to both treatment and prevention of diabetes among the Cree. A number of suggestions were made to us by HCPs on how to overcome and dispel this understandable illusion. These included one-to-one discussions of its effects and complications with those who had been recently diagnosed with the disease; encouraging patients who might be predisposed to develop the disease to talk to diabetics about their condition; and handing out leaflets and other literature on diabetes.

As our research progressed, however, it became clear that all the HCPs we talked to saw forms of education as the key to making visible the immediate and long-term effects of diabetes. Indeed, the majority argued that there was no alternative other than to establish community-wide programs for the provision of regular health education as a central component in any campaign on diabetes prevention.

Education and diabetes

It was common for HCPs to stress the role of health education in devising programs of treatment and prevention aimed at reducing both the incidence and prevalence of diabetes among the Cree. There were various reasons given for this, but the most compelling we heard was that within the Cree communities where HCPs lived and worked there was often a mixture of misapprehension, confusion, or ignorance about diabetes. This stemmed, they believed, from a general lack of knowledge and

understanding among the Cree about the nature of the disease. Without such familiarity and understanding, it was felt that neither programs of prevention nor treatment could be effective. This was for two reasons. First, knowledge and understanding was crucial in reducing the stigma that many Cree with diabetes attached to the disease. Second, it formed the basis for encouraging individuals to develop behaviours that were conducive to controlling the disease. As a nutritionist explained to us:

First I tell people that they don't have to be shy about it, because it is a disease, it's not curable but you can control it. It's something you have the rest of your life, so you can take time to be able to be comfortable with it and be able to control it and understand what is going on with their body. But they have a long time to learn to deal with that and after that they can feel more comfortable about it. I'll tell them that nobody knows except them – it's not written on their face, because if they go to meetings, they're sometimes afraid that everybody will point to them, stigmatize them.

As part of the larger study we referred to above, we observed that the “stigma” of having diabetes is a well-known phenomenon within the Cree communities. Most important among Cree beliefs of causation of diabetes is the idea that it is a disease of the “white man,” his food, and culture. Diabetes was therefore seen as a condition to be “kept hidden” (Boston et al., 1997). Becoming “comfortable about it” and “able to control it” was only possible therefore if the Cree understood “what is going on with their body.” In helping her patients to understand, pictures and metaphors were used to show how the pancreas is like a “sleepy worm” that is not doing its job processing sugar. However, although HCPs recognized that the creation and dissemination of such knowledge and understanding was central to their work on diabetes, we found that there were two distinct approaches to how this might be produced. It is worth briefly considering these as they have significant implications for future policy and program development on diabetes.

Among the majority of HCPs we interviewed the dominant view on how best to educate individuals on diabetes was through direct clinical contact that focused on teaching patients how to respond to their various presenting problems. One HCP gave us an example of how this process emerged as part of his clinical practice:

Every time I see a patient I always tell them to look at their feet – to me the most important thing in the diabetic is their feet – because if you don't have your feet you can't go around, walking around. So I emphasize the feet all the time. Say it's poor circulation to your feet – I give them the story, because sometimes you cannot feel your feet if they have really poor circulation. For example, if something's rubbing them. So you have to check your feet every day – so wash your feet every day and I tell them the way to cut their nails – don't cut your nails right around, cut it straight across.

For many HCPs this educative process constituted a central and valuable part of their work in dealing with their patients. While they claimed that it was effective it was nevertheless limited to relatively short periods when patients visited the clinic (and to actual diabetics). As one HCP explained:

Our clinic, especially, is so busy that the three nurses see an average of 60 patients a day. And there's not the time to sit down for 45 minutes with a diabetic and say, well, this is what you should do, yeah, you're doing really good on that, but we'd like to see you do a little better on this.

Beyond this small clientele their work had few, if any, repercussions. However, among a minority of HCPs there was a growing recognition that other mechanisms and methods outside of their clinical practice might be employed in a campaign of diabetes awareness that would have wider effects within the communities of the James Bay. As one HCP noted, these approaches tended to focus on the promotion of diabetes awareness within traditional decision-making bodies of the Cree:

We've tried a few things, well, we've had our trials and errors trying to launch a diabetes awareness week which is lots of work with lots of things to get ready, asking people as an example, to come up from Montreal. It was hard to go and grab people's interest about it even if they would say "We need more information, we want more information." ... We have to look at another way to try and reach the people... I think now more and more, the band levels, the band council has to be more aware about the problem. I think this is changing, because there's been meetings with the band chiefs and a few doctors and I think now they're starting to realize – that they're wanting things to start happening in the communities.

Outside of the band councils other institutions were often mentioned in the development of a broader strategy aimed at diabetes prevention. In particular, the Cree Board of Education and its schools were seen as potential sites for the dissemination of knowledge about diabetes to young people. As one interviewee put it, "You have to start early in school."

These and other similar responses to our questions suggested that some HCPs were beginning to envision the construction and development of educational policies and programs that would support and could be coordinated with their clinical practice on diabetes. However, such preventive initiatives for this group had to be generated from within the wider Cree community itself. As one HCP convincingly argued:

When you keep bringing answers, this is not what they need. It doesn't work. It has to come from... their ways. You don't know what are the ways but there's ways for us to have them ask themselves questions and then from these questions, find their own answers. It might not be the one I wanted... but you have to live with that too.

Drawing upon Cree knowledge and culture was therefore crucial not because this was somehow endowed with some special properties, but that it would allow the development of "their own answers" and self-determination over the formulation and development of both formal and informal educational processes and practices concerning diabetes prevention and treatment. Our general observation, then, is that diabetes prevention and treatment relies not only upon the availability of medical personnel, resources, and finance, but on the development of forms of knowledge and understanding concerning the disease which make sense from the standpoint of the Cree.

Conclusion

Our research on healthcare professionals' perspectives points to several issues that need to be addressed in the construction and implementation of policies and programs concerning diabetes treatment and prevention within aboriginal communities. The first of these relates to education and orientation of HCPs. That is, prior to their arrival in James Bay many HCPs felt that while they had received a good standard clinical

education in the diagnosis and treatment of diabetes, such education did not equip them well for understanding how the disease was perceived and experienced by aboriginal people. This deficit in their education was further compounded on arrival in James Bay through lack of any systematic program of orientation or “acculturation.” Indeed, most HCPs reported to us that it was a question of “learn-as-you-go” in attempting to discover how they could live and work among the Cree.

A second area for consideration that we identified was the way in which the concept of “lifestyle” was used by HCPs to understand the growing incidence and prevalence of diabetes among the Cree. Our evidence suggests that among the majority of HCPs the concept of lifestyle was shaped largely by perspectives generated from within a southern context. As we noted, this tended to foster a conception of diabetes as if it were a problem primarily rooted in patterns of individual behaviour and action that were separated from wider socioeconomic processes affecting the Cree communities over the last two decades. Reflecting the concerns of HCPs, the concept of lifestyle should be expanded to account for the fact that individual forms of behaviour are profoundly influenced by forces in both the physical and social environment. Above all else, the rapid incursion of southern culture into the Cree communities that eventuated from the signing of the James Bay Agreement, and the particular socioeconomic dynamics and tensions it has generated, have to be taken into consideration when developing policies and programs on diabetes.

Food and diet formed a third element of our findings. Our primary observation was that traditional Cree foods and diet constituted not only the focus of social and cultural events, but the reproduction of traditional social and community relations among the Cree. Having a goose feast is also a way of keeping in touch with the past. However, our findings suggest that HCPs are unclear over how and in what ways traditional foods might be integrated within dietary regimes for diabetics. They also point to the way in which dietary regimes developed for diabetics from within a conventional medical model problematize foods that constitute the traditional Cree diet. From within this model, bear, beaver, or goose meat are equated with southern junk food such as hamburgers or hotdogs. Thus, consumption of food that celebrates and confirms traditional bonds and rights is transformed into the source of ill health and disease, thereby inverting its historical relationship to Cree culture and society. The recognition that dominant approaches to diabetic control and nutrition worked to stigmatize Cree foods in this way was a major source of concern for some of the HCPs we talked to. Recent research on the effects of traditional foods on the metabolism of Native Americans suggests that this concern is not misplaced. Nabhan’s (1998) study on the traditional foods of the O’odham of Arizona indicates that they have a crucial role in reducing blood-sugar levels or prolonging “the period over which sugar is absorbed into the blood.” As he goes on to note, “For the O’odham and other recently westernised indigenous peoples, a return to a diet similar to their traditional one is no nostalgic notion; it may, in fact, be a nutritional and survival imperative” (p. 175).

HCPs also reported to us that although diabetes was a growing and significant healthcare issue among the Cree, it was only one of many social problems that some of their patients confronted. They argued that this not only posed difficulties for their patients in controlling the disease, but that it implied an approach to treatment and prevention that went beyond the confines of formal clinical practice. Indeed, because of its “invisible” character, HCPs have argued for a response to diabetes where clinical practice worked in concert with community-based strategies in combating the spread of the disease.

Finally, the HCPs we talked to felt that there was still a lack of understanding and knowledge of diabetes among the James Bay Cree. This required that future policies and programs aimed at diabetes prevention and treatment should focus on facilitating community-wide mechanisms that would educate and inform the Cree about what the disease was and how to prevent it. However, it was also emphasized to us that such knowledge and understanding would be better received and more effective if it was framed from the perspective of Cree ways of knowing and doing.

We believe that further research on these issues is required to inform healthcare policy for aboriginal populations. In particular, we feel that future research might focus on how aboriginal experience, knowledge, and understandings of health and illness might prefigure and contribute to the generation of forms of healthcare policy and provision for aboriginal communities. In relation to health professional education, our study suggests that much could be done by universities, community colleges, and other accredited bodies to reform curricula and programs of education so that they better address the needs of aboriginal people. Such reform, as our findings suggest, implies that time and space be given over to considering how aboriginal people can embrace their own understanding and experience of healing within a medical paradigm that arises from another context and culture.

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