

**‘THE CREE EXPERIENCE OF DIABETES: A QUALITATIVE STUDY OF THE IMPACT OF DIABETES
AMONG THE JAMES BAY CREE’**

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INTRODUCTION

This study was commissioned by the Cree Board of Health and Social Services of James Bay (CBHSSJB) in June 1995. It forms part of an ongoing series of activities that are aimed at combating the growing incidence and prevalence of diabetes among the James Bay Cree. This has included: a prevalence survey to evaluate a pilot diabetes education program implemented by community health representatives (CHRs); the hiring of a diabetes nurse educator to support and improve ongoing patient care; a gestational diabetes project aimed at nutritional counseling of pregnant Cree women; and most recently, the construction of a diabetes register from May 1996. Among the Cree chiefs there has also been a growing political will to make diabetes a priority health care issue. This has helped generate a growing range of activities sponsored by community councils, such as a diabetes awareness week, weight loss contests, and the development of plans for walking paths and other forms of physical activity. In conjunction with the First Nations Diabetes Declaration (1995), it is hoped that these and other initiatives will begin to foster an awareness among the Cree that they must begin to act against this disease now.

However, despite the determination of the CBHSSJB to prevent the growth of diabetes among the Cree, there has also been an emerging recognition that existing preventative measures and some treatments have not been as effective as in the south. The implication is that forms of health care and education proven in the south may not be suitable for the particular cultural context that constitutes the Cree communities of the James Bay. Consequently, the purpose of this research project has been to investigate and explore how forms of health care provision aimed at the prevention of diabetes can be constructed by the CBHSSJB using Cree understandings and experience of the disease. This was considered an urgent priority for two reasons. First, as with other Aboriginal peoples the incidence and prevalence of diabetes has

grown dramatically in the last two decades among the Cree, particularly since the signing of the James Bay Agreement with the Quebec government (November, 1975). The growth of the disease in the James Bay communities is already being reflected in increased expenditures being allocated to diabetes prevention. This amount is likely to further increase in the future with expenditures on monitors, laboratory testing, physician and nurse consultations, hospitalisations, dialysis, evaluations, and medical visits outside the territory. Second, despite the will and financial commitment of the CBHSSJB to confront what appears to be a looming epidemic, there is a justified uncertainty over spending large amounts of money on programmes and services which, while tested and proved in the south, may not be effective or efficient in the north. The use of glucometers is a case in point.

In recent years glucometers have been used as a key method to allow diabetics to measure their blood sugar levels on a regular basis, thereby establishing a strong connection between diabetes and 'unhealthy' eating habits. The advantage of this method is that once taught how to use the instrument, patients acquire a sense of control and responsibility over monitoring their blood sugar and eating habits that adversely affect it. However, we must also consider that if a glucometer is given to every diabetic and he/she only uses it once a day and checks it is accurate, once a week it would cost the CBHSSJB \$500,000 per annum.¹ If patients chose to use it four times in a day, this figure would quadruple! We also have to account for two other factors. A multitude of other variables are concerned in controlling diabetes. That is, the use of glucometers can only amount to one element in a broader strategy of prevention. Second, as this

¹ A box of 50 strips costs \$40

If a patient monitors his/her blood sugar once per day the cost per year for strips would be

$$\frac{365 \times \$40}{50 \text{ strips}} = \$292 \text{ (approximately } \$300/\text{year/meter)}$$

If 10% of Cree have diabetes approximately 1,000 meters would be in use and the cost would be \$300,000

study shows, there is a widespread sense of shame and stigma which many Cree diabetics feel about their disease. With such strong negative feelings constraining public admission of their condition (to family and friends), we must ask whether a glucometer will be used effectively, or if at all. In the face of these financial and cultural constraints, we have to consider whether this form of medical intervention is culturally appropriate and cost-effective on a wide-scale basis. Before developing policies and programmes that attempt to stem the growth of diabetes therefore, we have to examine how the Cree understand and are currently responding to the disease. Health care policy and provision can then build upon the knowledge and experience that the Cree already possess of diabetes. It was in the light of these difficulties and needs that this project was conceived and implemented.

Consequently, the purpose of this study has been to ascertain how the Cree communities of the James Bay viewed, interpreted, and handled the growing incidence of diabetes among their people. That is, its primary emphasis has been to give expression to the understandings and experiences that the Cree have of the impact of diabetes on their everyday lives and communities. With this focus in mind, the research has had four aims. First, to encourage the active participation of health care professionals (HCPs) and the Cree communities in defining the research problem and ways of addressing it. Second, to reveal strengths/barriers that pertain to the effective and efficient implementation of diabetes prevention and treatment programmes within the Cree communities. Third, to indicate courses of action and forms of organisation that will overcome potential barriers to effective treatment and prevention of diabetes. Fourth, to make recommendations on how the findings of the research may be usefully incorporated within the provision of preventative programmes on diabetes.

If the patients check that their meter was accurate on a weekly basis, the cost for control solutions, needles and other

These aims necessitated a form of social research that not only relied upon qualitative or ethnographic forms of inquiry, but also required the active participation of members of the Cree community in the research process and its product. For this reason, the collaboration of the nine Community Health Representatives (CHRs) of the Cree communities of the James Bay was considered crucial for the implementation and development of this study. With their participation as co-researchers, this study was able to gain a unique and often surprising set of insights into the cultural understandings that constitute the Cree experience of diabetes. It is hoped that its findings will form the basis for the future development of policies, programs, and services that reflect a Cree approach to the problem of diabetes.

The report is organised into three sections. The first section describes and analyses data gathered by the CHRs on Cree patients with diabetes. This seeks to explore and elucidate not only their understandings and attitudes toward the disease, but also reveals how they attempt to manage it on a day-to-day basis. In particular, it reveals that the Cree experience of diabetes is organised in different ways from Canadians in the south. The second section provides an account of the views and perspectives of health care practitioners (HCPs: i. e. doctors, nurses, dentists, etc.,) who deal with diabetes in the course of their work within the Cree communities of the James Bay. The third and final section comprises the ‘executive summary.’ This acts as a conclusion for the report in that it brings together the main findings of the research and the recommendations arising from it. For readers who want a brief overview and summary of the study’s findings, they should commence here.

related supplies would be \$200,000 per year. This assumes that the glucometers are free and not the quoted \$40.

ORGANISATION AND CONDUCT OF THE RESEARCH

The research for this study was conducted between September 1995 and March 1996 by a team of three ethnographers and a physician from McGill University and nine Cree Community Health Representatives (CHRs) of the Cree Board of Health and Social Services of James Bay (CBHSSJB). Adopting a qualitative approach to social inquiry, the research for this study focused on the collection of data in the form of interviews, participant observation, fieldnotes, and documentary evidence. After translation and transcription, the data was organised on a computer and analysed according to emerging themes and categories that were relevant to the aims of the study (see introduction). The data contained within these themes and categories were then used as a basis from which to construct the findings presented in this report.

From its inception the study has had two, interrelated, strands which have converged on the production of knowledge and understanding to inform CBHSSJB policy and program provision concerning the spread of diabetes mellitus among the Cree population of James Bay. 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 different communities of the James Bay. While the data gathering for this part of the study was conducted by the CHRs, its organisation and implementation evolved from an on-going collaborative process with the McGill researchers. This collaborative process proved vital not only to the construction of a shared understanding and set of skills about how to approach our research problem, it also provides the basis for our claims to validity concerning our findings. That is, the intimate knowledge and tacit cultural understandings brought to this study of Cree culture and community by the CHRs allowed us to explore the impact of diabetes as it is perceived and experienced by the Cree.

The collaborative approach that this study adopted arose out of a series of workshops involving the McGill researchers and CHRs between September 1995 and February 1996. The aim of the workshops was to provide a grounding in, and familiarity with, qualitative research techniques for the CHRs, so that they could begin to collect data from their different communities for the study (see Appendix 1). Drawing upon their own personal and professional experience of Cree culture, the CHRs also played a key role in developing - sometimes re-defining - the orientation of the research as it progressed. In this way the workshops provided a forum for the mutual exchange of ideas, knowledge, understanding, and skills that allowed for the research agenda to reflect a Cree standpoint on issues pertaining to diabetes. For example, the themes and issues explored through the interview schedules used with Cree diabetics arose out of a series of on-going discussions with the CHRs. As the research progressed and data was collected and analysed, these themes were developed, modified, and shifted their focus (see Appendix II). This approach also applied to the CHRs fieldwork notebooks, in which they gathered observational and other relevant data.

For the Cree component of the study, all nine CHRs were interviewed on at least two occasions, either individually or as part of a roundtable discussion by the McGill researchers. Once the CHRs had undergone initial training in qualitative data techniques, they then began to collect data from their different communities. Because of other demands placed on their time (through work and training), it was agreed that they should interview three Cree diabetics each (i. e. 27 interviews) for one hour. These interviews and fieldnotes then formed the basis for a second workshop in which the CHRs and McGill researchers began to analyse and construct themes and categories from the data. The findings of this workshop provided the basis for a second round of interviews that not only followed-up existing lines of inquiry explored through

the original interview schedule, but also focused on emergent or unanticipated topics for investigation. Consequently, the CHRs conducted a second round of interviews with two Cree diabetics each (i. e. 18) who were again interviewed for one hour. For the third and final workshop in February 1996, all interviews, fieldnotes and other relevant data were collated and analysed by the CHRs and McGill researchers for the purposes of producing this report. Its structure, content, themes, and foci were determined there.

In parallel with the research on the Cree, a member of the McGill team conducted a separate study on health care practitioners' (HCPs) understandings and views of the spread of diabetes among the Cree communities of James Bay. 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 health care 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.

A wide range of HCPs were interviewed, including: nine physicians; the director of professional services (DPS); ten nurses; two nutritionists; one dietician; three dentists; one community social worker; and a human resources manager. While a quarter of those interviewed had between 2-5 years experience working in the north, the majority had from five to 22 years. Interviews were conducted on visits to Chisasibi with an interview schedule that had been developed in consultation with HCPs who had working experience of the north and some knowledge of diabetes as it affected aboriginal populations (see Appendix III). All interviews were tape-recorded and had a duration of between one and two hours. Where necessary, follow-

up interviews were arranged on an ad-hoc basis to provide illumination or clarification on particular issues in the data. Finally, data from this strand of the study was analysed by the McGill researchers and its emergent themes/issues used to inform the development of the research agenda pursued in collaboration with the CHRs.

DIABETES AND THE CREE COMMUNITY

The Cree community is broadly defined as patients, families, community members, community health representatives and elders. Representatives of each of these sectors of the community were interviewed. As stated in the introduction, we saw the involvement and position of the community health representatives (CHR) as crucial to gaining a 'window' and direct link

to the perspectives, experiences and cultural understandings that the Cree people have of diabetes, its causes, prevention and treatment. We believed that by creating a sense of 'ownership' of the research process and its product, a more nuanced and deeper understanding of the community processes contributing to diabetes could be gained.

We have also concluded that the CHR's data contribution must be viewed and understood as arising from the community context. Community Health Representatives are themselves an integral part of the communities, as well as having personal and family experiences with diabetes. The CHRs were also instrumental in interpreting and clarifying issues and ensuring the validity of the findings. Again, we have remained bound by issues of ethics and confidentiality and, therefore, for the sake of anonymity, have included the CHR data with that of the larger Cree community in the overall research findings.

The central themes which emerged were broadly concerned with differences in communication in the context of translating knowledge into usable and practical information. In particular, these differences in communication between the Health Care Professionals and Cree patients were rooted in differences of understanding concerning: verbal communication; food; lifestyle; health and illness beliefs; and participation in policy and decision-making. We discuss these themes arising from the data below.

Communication

The most common barrier identified was communication. This was not perceived as only between the health system and Cree community but also within segments of the community itself. From the point of view of the CHRs and those they interviewed, the presence of diabetes places a barrier to communication at all levels of community organization. One area of communication difficulty relates in particular to the roles of family members within families.

The presence of diabetes potentially inverts status within many traditional families when children have different lifestyle habits (e. g. use of non-traditional foods) from those of their parents. Moreover, it creates tension within families. This is also manifested when young people are seen as 'educated' versus the traditional education and wisdom inherent in Cree family life.

As one man put it:

The young people, with a lot of education, know more about diabetes Older people have the experience because they have lived ... and I think they should share their knowledge ... We should talk together and everyone would benefit.

An additional factor in relation to the accessibility of traditional foods and to the broader issue of communication was that of language. Language misunderstanding was cited as a common barrier to the effectiveness of existing services. Perceived solutions lay in "knowing how to read food labels", the need for translation and assistance in knowing how to interpret differences between glucose and sugar for example. Language and meaning barriers were cited in "not everyone knows exactly how medication (actually) works", or "how the process of treatment and prevention happens."

Additionally, discussion of relevant beliefs such as health and illness, lifestyle and food, are seriously compromised by differing family/generational perceptions and beliefs surrounding lifestyle, food habits, etc.

From the point of view of many families, the condition of diabetes also functions to separate and marginalise family members from each other, from other families and from their local communities. The condition of diabetes is seen as a condition to be "kept hidden", "a secret" from family and friends, and "a stigma." Indeed, for many Cree diabetes entailed a sense of embarrassment, uneasiness, and even shame. For example, many respondents talked about

feelings of isolation in not being able to join in the social activity of eating - a vital pulse on the maintenance of family cohesion and family unity. As one person put it:

They'll talk about it in my community, they'll talk about it as a subject, but they won't necessarily say, "me, I have it", you know? [...] Now slowly they're starting to build up, but as an individual you keep it hidden. It's mainly hidden, I think.

Some respondents also felt that the Cree must “eat food of the white man which is not good for the Cree.” Moreover, feasts, an integral part of Cree life and Cree heritage cannot be fully enjoyed or receive full participation by Cree with diabetes.

Additionally, there were reports of perceived incongruence in communication between patients and health care professionals. At the broadest level, these concerns seem to be associated with a greater need to communicate accurately and meaningfully. As a Cree diabetic put it:

We were told to eat a lot of salads. It is so different from our traditional diet eat more tomatoes, eat more celery, eat more pears ... *we don't even have Cree words for those vegetables"*

And as another put it:

Since she (patient) nods when you talk to her, the nurse thinks she speaks English and she never had an interpreter with her. She can say words in English, but doesn't express herself well in English as well as Cree. And I guess she found out she was always being congratulated for her weight loss.

More specifically, communication problems and cultural misunderstandings were identified as existing between health care professionals and Cree patients.

Food habits and food beliefs

Of the latter issues, food habits and food beliefs were most commonly identified as the greatest barrier to shared knowledge between the HCPs and the community. Problems with mutual understanding of appropriate food were frequently identified. We did ask if people found it difficult to acquire food that they liked (hoping to open up further discussion). In this

connection, several people suggested that food considered 'good' for diabetes was not considered 'good' for Cree food beliefs and habits. Food considered good for a healthy Cree lifestyle was viewed as likely to be fatty meat from goose, bear, duck, caribou, raw ptarmigan or fatty fish such as char or trout. Several people suggested that food such as vegetables and salads, despite their perceived high quality by the health care staff, "did not seem to taste right." As one person reflected:

On the diet they say you should eat lots of vegetables and my stomach growls and I still feel hungry afterwards ... but when I have a good diet in fats, I feel good. I feel as though I've eaten.

Indeed, it seemed that such food was widely regarded by the Cree as constituting "muskrat food." And whereas the avoidance of fat in one's diet was understood to be important within the belief system of the southern diabetic education, fat was nevertheless perceived as "necessary", "good", "nourishing" from the health perspective of the Cree person. Indeed, one of the CHRs was told a story of a Cree man who went south to Montreal for the first time. Stopping off at a restaurant for a beef steak, he was asked by the waiter how he would like it cooked, 'With a lot of fat!' was his response. It should be emphasised that notions about 'fatty foods' are fundamental aspects of Cree conceptualisation of the causes and cures of illness and the maintenance of health. Therefore, by eating certain foods, such as fat (ideally found in goose, bear or beaver), the patient is trying to get better, rather than worse. As one person puts it: "people tend to spend their money on chicken or beef. Vegetables are sort of last." These issues were perceived as problematic when avoidance is combined with cultural tastes resulting in compromised nutrition, just at a time when a balanced diet may be necessary for the prevention and alleviation of diabetes.

Differing perceptions of lifestyle

Moving to perceptions of lifestyle, we have found frequently reported difficulties centring on differing perceptions of cultural mores between the HCPs and the Cree community. Respondents informed us that while diabetic teaching requires strict maintenance of a 'diabetic' meal plan, for Cree people, "to be polite and respectful" still means to join in social eating. To openly "refuse food is to be disrespectful". From the point of view of community members, the act of refusing food in social and family life is synonymous with the act of separating a Cree person from his/her family and community life. As one person put it, "to offer food, it's an offer of kindness, to refuse food is to refuse a person's kindness." Other reports related to the importance of participation in feasts and the sense of "feeling different."

They had a feast [...] we got all kinds of food from them (the family) and when I sat down mine was already in tin foil [...] and it was a bit dry [...] no fat [...] a piece of meat [...] it hurt a bit, you know?

Health and illness beliefs

Most important among the beliefs of causation of diabetes is the notion that diabetes is a disease of the 'whiteman', and comes from the white man's blood. It is not clear whether this was perceived to be a 'virus' brought in by the white man or some other agent. There were several reports which gave accounts of Cree perceptions of health and illness "before the white man came" or "before the James Bay Agreement."

The majority of informants still conceptualized healing related to diabetes within a Cree worldview, even if they reported "following the teaching" of the HCPs. Although our purpose was to assess the way people use the services they currently have available, we also asked initial questions about Cree healing experiences. While there were no specific reports of the usage of alternate healing practices, the majority of respondents reported differing cultural perceptions of

`healing' and wellness that are perceived to be more healthy. There are reports of specific efforts to eat different and alternate foods to those suggested by the Health System. Reports describe people feeling "stronger" and "feeling good" after eating such foods. We were reminded by informants that the disease (diabetes) "is getting worse and worse", that it is a "silent disease" which has accompanied "the whiteman" and which has accelerated in the last twenty years. (In almost all cases, this event was associated with the "decline of bush life" and hunting, walking fishing and food from the land; and the James Bay project).

Even when informants described the current practice of "going into the bush" they admitted to feelings of "energy" and "rejuvenation". This feeling was described as "stemming from the time when Cree people followed the seasons rather than a calendar." As one put it:

If you're here at that time of the year, the town just empties out and the people have this urgency to get ready and go [in the bush]. Everybody's talking about it. It's just a feeling of rejuvenation. One of the best times of the year, really.

Moreover, the concept of "extra weight" was understood to have a direct relationship to the perceived necessity to (healthily) store vital body energy. As one person put it, "to be boney is not healthy, to be fat is healthy."² At times these beliefs were related in direct connection to the cultural misunderstandings between patients and HCPs. As one patient put it:

The nurse is so happy because I'm losing weight. I'm worried about my weight loss, it's too rapid [...] and the nurse thinks I'm exercising [to lose weight]

And as another patient put it:

And even just general overweight is not seen as a problem [...] here it's seen as prospering. Doing well.

While many respondents reported an understanding of the underlying rationale for the use of glucometers for blood sugar testing, there was also a reported ambivalence on how

frequently glucometers were actually used or how strictly dietary regimes were followed. While some respondents reported that they followed "the teaching" (of the HCPs), others claimed that they "knew" but did not practice. It seems crucial to interpreting these data to recognize that even though the majority of respondents use the health care system, such use does not arise out of a sense of familiarity or ease on their part. That is, choices of health and illness management are still being made very much from within a Cree cultural context. An important finding is that most Cree people regard southern and Cree approaches to health and illness as separate and therefore do not report the use of alternate practices with any regularity. There are also reports of "fearfulness" of diabetes, and "mistrust" of everything since the James Bay project and arguments that white man's medicine does not work.

Cree decision-making and the policy process

Another finding for the majority of respondents was in the area of community control over decision-making. There was considerable discussion which arose out of questions raised on lifestyle changes since the James Bay Agreement. These revealed reports which emphasized a sense of under-involvement in broad decision-making processes in both local and broad level policy issues. From the data findings, there is revealed here little evidence of the Cree developing their own responses to diabetes, either in the area of its causation and prevention or in the area of health care. This was not simply confined to relationships between health care professionals and patients but appears to be of a broader and more complex nature relating to the organisation of Cree culture and society itself. There were also reports of what was termed "social divisions among the Cree." While these reports related more directly to changes in

² It is important to understand that the use of 'fat' in this context meant being robust or carrying a little extra weight which made one stronger and more capable of going about everyday activities. Being excessively over weight or obese is not desired by the Cree.

lifestyle since the James Bay Agreement, these accounts nevertheless were indicative of problems of communication and separation within the communities. As two respondents observed:

They rarely listen to what we have to say, when we say something it's never done.

The elders want the chief to be here all the time - but the chief has so much business ... so many obligations that he can't be here all the time.

With regard to decision-making issues, many admitted to feelings of "helplessness" and a sense of hopelessness. Reflecting this sense of powerlessness one Cree elder noted that:

I never thought my life would be like this [...] when I look outside I just see another house, I don't see the river or the lake [...] I never thought I'd be stuck in somebody's living room.

Yet others felt a sense of alienation from formal decision-making processes:

I saw three elders - they were sitting there and I said to them, "Did you go to the meeting last night?" And they sort of laughed and one of them said, "Yeah, I went to the meeting for about half an hour or so and then went home." And I said, "Why? Why?" And so they said, "What's the point? They're the ones who make the decisions.

While we were unable to pursue these problem areas in some depth, it was evident that the majority of respondents were initially unclear about how they could influence, or become actively involved in decision-making regarding the policy process relating to diabetes. Nevertheless, there was an expressed desire for greater involvement in the policy and program process at all levels. Informants suggested the need for greater shared access to knowledge about diabetes between respective chiefs and their local communities. Some solutions were suggested, such as encouraging greater Cree participation in health shows, radio talks and more active involvement in these by band chiefs and the band council.

In the latter phase of the research project, interview and observation data revealed a number of other patterns relating to potential solutions as to how people perceived becoming involved in the policy and program process with regard to diabetes prevention and treatment.

Accessibility to Cree food

The issue of lack of access to Cree food was consistently revealed. People asked for alternative ways of identifying the special needs of Cree patients with diabetes. Others admitted to wanting to make changes from fast foods to more natural Cree foods. As one person put it, "At least natural store bought food [would be better] than microwavable marconi." Participants also aspired to finding solutions to the problem of scarcity of store bought game (rabbit, goose, beaver), where it was hoped that the latter could become more available. It was perceived that items which are fundamental to Cree food habits need to be identified and encompassed within dietary regimes and education programs. These were perceived as solutions to the additional problems of foods which are universally disliked by Cree people, such as vegetables.

Respondents emphasized this problem at length. It is interpreted that this is a matter not only of adequate nutrition. It is also a matter of health maintenance and well-being. Food which actually tastes good, or can be used to modify food was perceived by the Cree to be an important part of "feeling well" or "feeling healthy". Having ready access to a meat based diet, better access to meat in stores, access to local or future developed trapping services, it is suggested, could go a long way to improving morale for both the patients, families and those who provide them with the food itself.

The need for food and diet teaching for Cree by Cree people was also expressed. It was suggested that nutrition teaching be integrated into senior elementary schools and junior high schools and taught by the Cree. Perceptions of "how to be involved" lay in the area of "having

diabetes sufferers themselves become involved in diabetes education." As one person put it:
"There is no better person to teach a Cree than a Cree ..."

Other forms of participatory involvement were described as the need for greater participation in the development of Cree educational materials. Participants suggested the compilation of a Cree cookbook for people with diabetes, Cree cooking classes, workshops and informal meetings in Cree, as well as diabetic support groups.

Summary

In summary, the most pressing issue arising from this study is that of communication. From the point of view of the CHRs and the Cree diabetics they interviewed, the presence of diabetes places barriers to communication at all levels of community and health organisation. Differences in communication between health care professionals (HCPs) and patients appear to be rooted in differences of understanding concerning food, lifestyle, health and illness beliefs, and modes of decision-making. Concern was also expressed about poor communication between various chiefs and their communities as a result of emerging "social divisions among the Cree." Specifically, there was a perceived need for more effective mechanisms to be devised for the transmission of policy and program knowledge from chiefs to their respective communities. Although there is some evidence of Cree involvement in the policy and program process, greater access could be achieved by including the Cree community in decision-making processes that shape health care provision concerning diabetes treatment and prevention.

HEALTH CARE PROFESSIONALS

For the purposes of consistency and clarity in this chapter, we use the term ‘Health Care Professional’ (HCP) to describe the people we interviewed who have as their vocation some responsibility for health care 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 health care services, in addition to physicians (in direct service working full time or as temporary replacements, as well as physicians providing in-service and support, back-up and training). Because the health care system is primarily organised, administered, and delivered by non-Cree, the CHRs were not included in this part of the study.

Professional orientation and training

One of the major findings of our research was that the majority of HCPs had received limited formal training on the clinical management of diabetes within different cultural contexts. That is, while HCPs acknowledged that their medical training provided them with a good medical understanding of the nature of diabetes, they expressed concern that it did not 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 training 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 [Chisasibi]. You know, how to treat the people and more practical things ... and then you realise that there are some things in the training that are different. So when you get to diabetes and very quickly realise 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 training was to acquire knowledge and skills on-the-job as part of their everyday work routines within the 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 training 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 and a book, 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 - who were predominantly drawn from a ‘white’ southern context - experienced a double deficit as newcomers to the Cree communities of the James Bay. First, their formal education and training did not sensitise 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 the James Bay. Second, they felt that this deficiency in their education and training was further compounded by the absence of any formal mechanisms (e. g. an orientation day, seminars, talks etc) for inducting them into Cree culture on their arrival in the James Bay. Providing them with brochures, books, and other forms of printed material was useful but could not a substitute for formal mechanisms of induction 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 health care 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 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 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. Either you're drinking or you're in jail, or you're husband's having an affair.

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 pace 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 sometimes 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 *mentalité* 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 *par 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.” One HCP with some considerable experience of working in the Cree communities of the James Bay put it like this:

The James Bay Agreement has effected a free-trade zone for the Cree and in that respect you can think of it as being a bit like NAFTA. The project has brought the road, television, telephone, cars, chainsaws, fridges, freezers and so on. It’s established an economic relationship where 10,000 Cree have to compete with sixteen million people in Quebec and Ontario. They [the Cree] are beginning to find their own feet ... for example, KEPA transport and other small enterprises, but it will take time.

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 socio-economic forces that were re-defining how the Cree were to live in the contemporary world.

While the effects of this 'change in lifestyle' brought many benefits, it was also recognised that such change had had subtle, but nevertheless profound, consequences for the way that the Cree had traditionally organised 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, this person 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.

Although a disease, diabetes was nevertheless 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 change and transformation since the hydro developments of the 1970s, diabetes was therefore a 'complex problem' which could not be reduced to individual behaviour or lifestyle alone. This way of re-conceptualising the links between diabetes and lifestyle has important implications. In particular, it recognises 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 reorganised their relationship to one another and most crucially, to that of the land. 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 programmes 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 serve 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. In particular, they emphasised 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. This special relationship to food was outlined for us by an HCP who was also a Cree. She remembered of 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 (a Cree elder) 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 in to account in the formulation and creation of preventative measures for diabetes. While this point is elaborated in the next chapter, we wish to emphasise it here as our findings suggest that many HCPs are still unclear about 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 stigmatise 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, being a diabetic requires both a new kind of self-discipline and energy which for a number of Cree confronting personal or family crises mitigated against the control of their disease. HCPs reported a range of issues mitigating against their Cree patients maintaining a careful regime of medication, diet, and exercise. For example, several HCPs we interviewed emphasised 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 training on diabetes, its causes, symptoms, and complications, there was a strong belief among some of the HCPs we talked to that such training 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 the James Bay face, health care and education aimed at diabetes would be seriously undermined.

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 didn't appear, at least in the short-term, to present 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 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. One HCP, who had developed diabetes while working in the James Bay, 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 developing 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 other 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. In particular, the central role of the CHRs in such a process was invariably underlined by those we spoke to.

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 of diabetes. Without such familiarity and understanding of the disease 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 which 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, stigmatise them.

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 - how the pancreas is like a "sleepy worm" that isn't doing its job processing sugar. However, although HCPs recognised 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 the way that this might be effected. 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 emphasise 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 small 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 which would have wider ripple 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 realise - 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 co-ordinated with their clinical practice on diabetes. However, such preventative 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 a sense of 'ownership' and self-determination over the formulation and development of both formal and informal educational processes and practices concerning diabetes prevention and treatment. In this, the Community Health Representatives were seen as playing a key role. Our general observation, then, is that diabetes prevention and treatment does not only rely upon the availability of medical personnel, resources, and finance, but the development of forms of knowledge and understanding concerning the disease which make sense from the standpoint of the Cree.

Summary

Our research on health care 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 in the James Bay. The first of these relates to training and orientation of HCPs. That is, prior to their arrival in the James Bay many HCPs felt that while they had received a good clinical training in the diagnosis and treatment of diabetes, such training did not equip them well for understanding how the disease was perceived and experienced by Aboriginal communities. This deficit in their training was further compounded

on arrival in the 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 largely shaped 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 socio-economic processes affecting the Cree over the last two decades. Reflecting the concerns of a smaller group 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. Factors such as Cree culture and history have to be observed and accounted for, therefore, in 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 the focus of not only 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 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. Further, HCPs expressed some concern that such foods tend to be excluded, if not stigmatised, by dominant approaches to diabetic control and nutrition.

HCPs also reported to us that although diabetes was a growing and significant health care 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 emphasised 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. Most HCPs we interviewed saw the work of the CHRs as pivotal in this respect.

EXECUTIVE SUMMARY³

Cultural Problems And Opportunities

By June 1995, it was apparent that diabetes in the Cree communities was reaching crisis proportions. Both the Cree and health care professionals were alarmed at the future impact of diabetes on the population if nothing was done to arrest the disease. This fear was associated with a sense of impotence to deal effectively with the disease and the risk of spending large amounts of money on services which might not be efficient in the north. A good example of this is the way that glucometers are seen to answer the problem of helping diabetics understand their disease and high blood sugars. A glucometer is a small machine, that a diabetic can carry with him in his pocket. He can use it at home or in the bush to check his blood sugar. If a glucometer was given to every diabetic and he only used it once a day and checked it once a week it would cost the community \$500,000/year. However, one of the most serious problems, of diabetes amongst the Cree, is the fact that it is a disease of which they are ashamed. If a patient has difficulty admitting to his family and friends that he has diabetes will he use a glucometer and will it have any effect on the disease? Therefore, we need to understand what are the strengths and barriers that exist in the community before developing programmes which will drain resources from other projects.

It was in the light of these difficulties and needs that this project was developed. (See attached Research Goals)

The most striking finding was the fact that health care professionals and the Cree (both health care professionals and patients) view the problem from very different standpoints. While many examples in the report discuss these differences, we provide two here to illustrate what we

³ An earlier version of this text was presented at a C.B.H.S.S.J.B. meeting, Whapmagoostui, 26th March 1996.

mean: Cree see goose (especially its fat) as good food and vegetables as ‘muskrat food,’ while non-Cree see goose fat as a ‘food to be avoided’ and eating vegetables as healthy; similarly non-Cree see eating as a matter of personal choice (lifestyle), while Cree feel that to openly refuse food is to be disrespectful by refusing a person’s kindness.

We believe this divide must be bridged and it is in forming the bridge that some of the answers to the problem of diabetes among the Cree community can begin to be tackled. A poster states ‘No one understands a Cree like a Cree.’ For health care professionals’ this implies that they need the active participation of the Cree in designing and developing diabetic programmes. Sometimes what is obvious to one can not be seen by another. One day an old man was eating berries by the river when along came a doctor, newly arrived to his village. The doctor asked what was he doing. “I am eating berries” he said. The doctor looked around for the bushes but saw none. “Where are the berries” he asked. “You are standing on them” replied the old man.

We recommend the establishment of a system of Cree ‘guides,’ mentors and tutors for all health care professionals working in the James Bay area. This will not only promote better understanding between the two cultures but help health care professionals adapt their services and programmes to Cree needs.

Similarly, we recommend the use of joint workshops where both groups are participants, to build solutions which take advantage of both sets of knowledge. These will also increase cross cultural understanding and are more likely to produce solutions that will work. In addition, now is the time to augment the role of the CHR’s and to expand their responsibilities and enhance their position. The recommendations relating to the CHR’s spring from the fact that both they and the community have spent enormous time and resources in their education and training. Not to exploit their unique position and to increase their input into all aspects of medicine as

practised would be a great loss. The central role that they played in this research project cannot be underestimated. This ranged from helping in the design of the questionnaire, performing interviews with Cree diabetics, analysing data and developing many recommendations. Their knowledge and understanding of the Cree are the cornerstone of this project.

Already efforts have been made to increase awareness to diabetes. This should be supported especially by respected members of the communities. In order to decrease the stigma attached to diabetes, it is important for these individuals to talk about it and to set an example, especially in communal activities such as dancing, walking, and so on.

Present initiatives to develop support groups for diabetics should be extended to their families and the concept of the Cree patient as an 'expert' on diabetes should be supported. With training they could become educators for both diabetics and the community.

Many of the health care professionals felt that they were inadequately trained for dealing with diabetes in the north. To overcome this a 'case management' approach might be developed. This would involve all concerned professionals, including CHRs, collaborating in patient care as a group in addition to their separate specialities. The aim of this approach would be to increase understanding of the patients particular medical and social problems as well as improving the provision of medical services.

An advisory board made up of health care professionals, diabetics, community/band council representatives and members of the school board should be set up to look at the problem from all angles.

Our final recommendations relate to nutrition. We found that the Cree have strong ties to their traditional foods which they gives them a sense of happiness and well-being. Unfortunately, these foods are rarely available in the store. Many store bought foods are highly processed, with

high fat and sugar content. If possible this should be remedied along with increasing the supply of mercury free fish. In addition people find it difficult to read labels since sugar may be called many things such as corn syrup, glucose, or fructose. As well, the packaging can be very misleading. It would be very helpful if a simple picture or symbol code could be developed (by the CHR's with help from the appropriate people) and stuck to the foods or the shelves.

Many of the instructions given to diabetics relate to measures. Traditional Cree cooking does not use these. It would be a worth while endeavour, and fun, to publish a book with good recipes and stories to keep the cook amused.

One of the saddest findings of this research was to discover that many diabetics felt ashamed of their disease. We have not had the opportunity to actively pursue this but it is obvious that if someone is told that he has a disease because he eats too much, eats the wrong foods and does not exercise it must be his own fault. If the treatment means that he becomes separate from his family and friends and can not even eat goose at celebrations, it is not surprising that the patient hides the disease, while also feeling guilty and ashamed of their condition.

To describe Cree food (goose fat) as 'bad' and 'unhealthy' won't be accepted by the Cree when it has saved them from starvation for many generations. When teaching about diabetes we must overcome these negative images being used We will not win the battle against diabetes by unconsciously blaming the patient or his culture for his disease. That is a road to failure.

The James Bay Project is seen by many Cree as something that has thrown their life off balance. They feel this balance must be regained. That is what we are working for. We cannot bring back the old ways, nor do we want to destroy what remains of them. But we do need to combine the modern and traditional ways to find a new balance.

Recommendations

Communication

- ◆ Set up a system of Cree tutors or mentors, for non-Cree health care professionals to help them understand the community, its values and approaches.
- ◆ Offer cross cultural workshops on how culture effects illness and how the Cree seek help and their response to treatment.
- ◆ Joint workshops for both Cree and non-Cree participants developed to enhance understanding between the two lifestyles. These should be based on solving specific problems and to develop policies using the strengths and weaknesses of both cultures.

Diabetes

- ◆ Bring diabetes in to the open through the media (radio, 'The Nation,' the Church etc.) to make it more acceptable to seek help and treatment and to increase the communities understanding of the disease.
- ◆ Make diabetes less of a stigma by having Band Chiefs, and other respected community members discuss it openly
- ◆ Band Chiefs to set healthy life-style example e.g. walking, dancing, smoking less etc.
- ◆ Develop diabetic support groups for patients and their families
- ◆ Train and support Cree diabetic patients to become 'experts' on the disease, how the medications work, how they cope with the disease, how they cook their food, and help them share their knowledge and experience with other diabetics and the community.
- ◆ Develop a 'case management' approach to diabetes, using a team of physician, nurse, CHR. and other available professionals
- ◆ Develop a diabetes advisory committee comprised of health care professionals (Cree and non-Cree). school board representatives, members of the Cree community with diabetes, representatives drawn from the Band Council, and respected members of the community

Nutrition

- ◆ Increase access to store bought food appropriate for developing healthier eating habits i.e. less high calorie fast foods. Make information readily available to the shopper e.g. a picture or symbol code system developed for each product to be put on the packets or shelves
- ◆ Increase access to store bought traditional Cree foods/mercury-free fish.

- ◆ Cree cookbook, Cree food cooking classes using Cree methods i.e. no measures and good stories
- ◆ More information on how to read food labels e.g. sugar, glucose, fructose
- ◆ Nutritional teaching at senior elementary level and junior high school level
- ◆ Increase diabetic education, prevention and nutrition at all school levels, particularly in cookery classes and in the more senior grades.

Expand the role of the CHR's

- ◆ Increase their role in the decision-making process by actively pursuing their input and ensuring that they are always invited to all meetings in their clinics. These meeting should be always conducted in a language they can understand.
- ◆ To exploit the knowledge and understanding of the CHR's in looking for solutions to medical problems. Use and develop their skills as cultural guides as well as translators.

Have CHR's on selection board for health care professionals