Effects of diabetes on the health of the Cree of Eeyou Istchee

What can be learned from linking the Cree Diabetes Information System (CDIS) with the Quebec Diabetes Surveillance System (QDSS)

Brief report of the joint project between CBHSSJB Public Health Department and the Institut national de santé publique du Québec

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Foreword to the Occasional Paper Series

The Occasional Paper Series includes public health reports produced for the Cree Board of Health and Social Services of James Bay that address a single topic, and, are either of small size, or are expected to have a limited distribution. Printing such reports in a series is a way to standardize their appearance and to help keep track of them.

Diabetes is one of the most pressing health issues today, not only in Eeyou Istchee, but also in many other Aboriginal communities and in Québec and Canada at large. Diabetes was not a population health problem forty years ago. Today it is one of the greatest challenges facing the Cree and other nations. The increase in Type 2 diabetes seems to be related to the cumulative effect of major changes in diet and nutrition, decline in physical activity, and an increased tendency towards overweight and obesity in the population. As the Canadian Diabetes Association website says:

> *"Aboriginal People are at high risk of Type 2 diabetes. The traditional lifestyle of Aboriginal peoples was active and included eating healthy foods. Today, lifestyles have changed and people are not as active and eat less healthy food. This is one reason why Aboriginal people have a much higher risk of type 2 diabetes than other Canadians."*

Until recently the direct link between quality of nutrition, weight,exercise and diabetes had not been definitely proven. Recently, Health Canada has reported that "two important studies [the Finnish Diabetes Prevention Study and the Diabetes Prevention Program in the U.S.A.] have proven that by eating a low-calorie diet with less fat, and increasing the time spent in moderate physical activity, people at risk for type 2 diabetes are able to cut that risk by more than half." [See www.canadian-health-network.ca]

Foreword to the report on Effects of Diabetes on the Health of the Cree of Eeyou Istchee

In 1996, the Cree Board of Health and Social Services of James Bay (CBHSSJB) began to track the number of people with diabetes in the region and to set up protocols and systems within the clinics to standardize diabetes treatment. Because of this experience, the Diabetes Initiative was invited, in 2000, to participate in the Aboriginal Diabetes Working Group (ADWG) of the National Diabetes Surveillance System (NDSS). The ADWG is comprised of people with technical experience in diabetes surveillance. As a result of this involvement on the ADWG, the CBHSSJB began to work more closely with the people running the Québec Diabetes Surveillance System (QDSS) at the Institut national de santé publique du Québec (INSPQ).

In the spring of 2002, the Board of the CBHSSJB invited the INSPQ to organize a research project to link the Cree Diabetes Information System (CDIS) into the QDSS. Although the CDIS provides information on the number of people with diabetes and the kinds of treatment they were receiving in the clinics, it has no information about the kinds of treatment people receive outside of the region. This information is particularly important for understanding the progression of complications in people with diabetes, and for planning appropriate services in the region. Complications of diabetes are serious and can not only lead to extreme forms of disability but also require highly specialized services from medical care to assisted living. To maintain the quality of life of people living with diabetes, the CBHSSJB not only needs excellent diabetes programs, but also information to be ready to meet future demands for services.

In response to the request from the CBHSSJB, the INSPQ wrote a proposal to the NDSS and received financing for the project. Importantly, the project was then approved by the Commission d'accès à l'information du Québec. After these steps were concluded, the CBHSSJB and the INSPQ signed a research agreement to define their mutual responsibilities and obligations concerning control of data and publication. Finally, the INSPQ signed an amendment, concerning the project, to their existing agreement with Health Canada.

This present document has been prepared for clinic staff and managers of the CBHSSJB. It is a summary of the 75-page technical report which can be obtained on the website of the INSPQ at

www.inspq.qc.ca. Together with the annual update from the Cree Diabetes Information System, the findings from this research project help us to better understand this "epidemic" in Eeyou Istchee and how the CBHSSJB should be responding to help people live better with diabetes and to prevent it.

Jill Torrie
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Introduction

Diabetes is one of the major health challenges facing Eeyou Istchee (EI) and the Cree Board of Health and Social Services of James Bay (CBHSSJB). The Cree Diabetes Information System (CDIS), formerly called the "Diabetes Registry", was developed by the CBHSSJB in 1996 with two purposes: to standardize how the clinics manage diabetes through a system of clinical flow sheets for each individual with diabetes, and to anonymously track the numbers and characteristics of people who have diabetes in Eeyou Istchee. One of the limitations of the CDIS is that it is not able to provide any information on hospital services and use of medical services.

Each province in Canada now has a surveillance system for tracking diabetes using health system administrative data (as part of the National Diabetes Surveillance System (NDSS)). For example, in Quebec, information on hospital services is reported in the MED-ECHO database of the Ministry of Health, while the RAMQ collects information on doctor's billings and the diagnoses associated with each billing. It also tracks the use of subsidized medications (although this is not pertinent for the Cree region). The NDSS definition of a "case" of diabetes is either two-physician billing or one hospitalization with a diagnosis of diabetes in a two-year period. In Northern communities, this system of identifying cases of diabetes does not work because most physicians are paid on a daily rate and do not bill the RAMQ for each consultation with a patient. As well, medications are not paid out of the RAMQ medication insurance program but by the CBHSSJB.

Under the strict supervision of the Commission d'accès à l'information du Québec, and the Ethics Committee of the CBHSSJB, the CDIS database was merged with the administrative databases (MEDECHO and RAMQ) for the period of 1996-2001. The goal was to try to enhance the scope of the information that could be obtained from each separate database (see Appendix 1 for the file linkage methodology).

The goals of the project were to:

- Determine whether it would be possible to merge the two databases.
- Determine to what extent the NDSS could measure the prevalence of diabetes in a Northern region by comparing it to the CDIS which reports the true prevalence of diabetes in EI.
- Provide information on how and why Cree with diabetes in EI are using hospitals and medical services (information that was previously not available using the existing CDIS database).
- Propose ways to improve the CBHSSJB CDIS.

Results

1. To what extent can the NDSS measure diabetes in EI?

Of the 1076 cases of type 1 or type 2 diabetes reported on the CDIS 2002 Annual Diabetes Update, 949 (88%) matched with the RAMQ database while 127 (12%) had incorrect or invalid RAMQ numbers, and could not be used. As noted in the 2003 Annual Diabetes Update, the CDIS coordinator was informed of the incorrect RAMQ numbers and all were corrected with the help of the community clinics. Subsequently, 15 cases of type 2 diabetes were removed from the CDIS database because they were registered twice (due to an error in the RAMQ number).

Of the 949 matched cases, 405 (45%) were identified in the NDSS database, This finding shows that the NDSS cannot be used as an adequate system to measure the prevalence of diabetes in Northern regions.

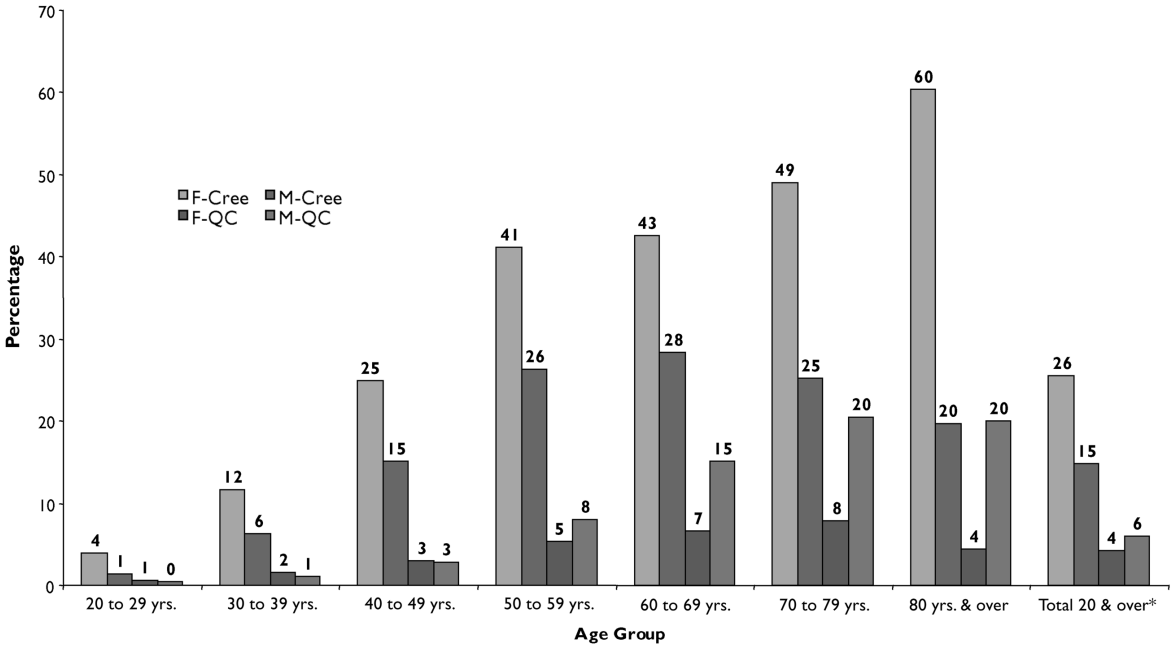
2. How many people had diabetes in EI in 2002?

The information from the CDIS was analyzed in more detail in order to give a better understanding of the severity of diabetes in Eeyou Ischee in 2002.

The crude prevalence of diabetes in Eeyou Istchee was 12.8% for Cree older than age 15, and 14.7% for Cree older than age 20. The crude prevalence of diabetes for women older than age 20 was 19% and for men was 11%.

The age-adjusted prevalence rate for age 20 and older (compared with the Quebec population for 1996) was 19.9%. This is four times higher than the Quebec prevalence rate of 4.9% for adults older than 20 diagnosed with diabetes (2001).

Graph 1 - Crude prevalence rate of diabetes (type 1 and type 2) of people aged 20 and over, according to age group and sex – for Eeyou Istchee and Quebec, 2002



*The total prevalences are adjusted to the age structure of the population of Quebec for 1996.

Source: Cree Diabetes Information System, NDSS, 2001 Statistics Canada Census of Population.

Sex distribution: 63% women (672 cases) 37% male (404 cases)

Duration of diabetes: The average time since diagnosis of diabetes was 7.9 years. (8.4 years for women, 7.0 years for men).

3. Complications of diabetes

The complications associated with diabetes identified in this study underestimate the true prevalence of diabetes-related complications. This report only discusses those complications that can be identified by administrative data files (that is, those that required hospitalization or consultation with a specialist) and only during the 5-year period included in this study. This excludes all reports on complications that did not require hospitalizations or specialist consultation, such as stable angina, leg ulcers, overt proteinuria and so forth, and all treatments received before 1996 and since 2001.

3.1 All hospitalizations

Hospitalization rates were calculated for the merged database and are presented below in table 2. We have shown that 48% of patients with diabetes were hospitalized at least once in the 5-year study period. This shows that this group of patients requires a high level of care.

Table 1 - Hospitalization rates for patients with diabetes on the CDIS (1995-96 to 2000-01).

Type of diabetes	Number of cases with at least one hospitalization	Proportion of cases with at least one hospitalization	Average number of hospitalizations
Types 1 and type 2 (n=949)	456	48%	1.5
Glucose intolerance[1] (n=176)	71	40%	1.2

Source: Cree Diabetes Information System, MED-ECHO.
[1]Glucose intolerance = Impaired Fasting Glucose (based on Fasting Glucose) or Impaired Glucose Tolerance (based on 2 hr PC OGTT). It does NOT include patients with a history of gestational diabetes.

An analysis of the patients with glucose intolerance (IFG or IGT) on the CDIS showed that 40% of patients with glucose intolerance were hospitalized at least once in the 5 year period. 14% of these hospitalizations were for cardiovascular conditions, with the remainder hospitalized for digestive (22%), non-specific (17%) respiratory (10%), and other diseases (24%). This shows that in our clinical practice, we may be underestimating the risk associated with glucose intolerance.

Table 2 shows a high variability of the rates of hospitalizations between the different communities (32% - 65%). The reasons for this variability will require further investigation.

Table 2 - Hospitalizations and transportation for patients with type 1 or type 2 diabetes, according to community of primary residence (1995-1996 to 2000-2001).

Community	Number of hospitalizations	Number of trips	Average duration of hospitalization, in days	Proportion of cases with at least one hospitalization
Chisasibi	214	96	6.9	49%
Eastmain	34	34	7.0	39%
Mistissini	347	347	6.2	51%
Nemaska	50	50	9.3	32%
Oujébougoumou	90	90	4.8	61%
Waskaganish	69	69	6.6	33%
Waswanipi	208	208	6.8	60%
Wemindji	51	51	6.8	40%
Whapmagoostui	36	36	6.2	65%
Outside EI	27	27	19.7	70%*
Total	**1126**	**1008**	**6.8**	**48%**

* This likely includes patients living outside EI for medical reasons.

Table 3 - **Referral centre for hospitalizations for cases of diabetes (type 1 and type 2) for the period 1995-96 to 2000-01.**

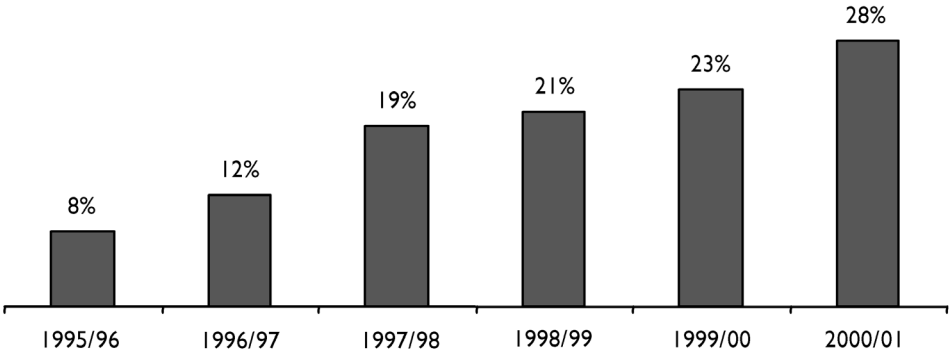
Hospital centre	Number of hospitalizations (N)	%
Centre hospitalier de Chibougamau	(473)	42%
Centre hospitalier de Val d'Or	(244)	22%
CSSS Chisasibi	(179)	16%
Hôtel-Dieu d'Amos	(54)	5%
Montreal General Hospital	(50)	%
Royal Victoria Hospital	(29)	3%
Other Montreal hospital centres	(53)	5%
Other hospital centres	(44)	4%
Total	**(1,126)**	**100%**

The administrative database for hospitalizations includes a "clinical severity indicator" that is calculated according to the numbers and types of diagnoses of each patient. This is a complex calculation that looks at the seriousness of the reason or reasons for hospitalization. Graph 2 shows that there was a steady increase in this seriousness scale among type 1 and type 2 cases hospitalized over the years, from 8% in 1995-1996 to 29% in 2001-2002.

Graph 2 - **Proportion of hospitalizations rated high/extreme according to the clinical severity index for cases of type 1 and type 2 diabetes entered in the Cree Diabetes Information System, by fiscal year, period 1995-96 to 2000-01.**

Source: Cree Diabetes Information System, MED-ECHO.

3.2 Hospitalizations for cardiovascular disease



63 patients (6.6%) with type 2 diabetes were hospitalized 147 times for cardiovascular disease (CV): myocardial infarct (heart attack), ischemic cardiomyopathy, angina, or congestive heart failure. There were more cases of CV hospitalizations for women than men, and the overall rates of CV hospitalizations increased over the study period. There was an average of 10.3 years between diagnosis of diabetes and first hospitalization for CV disease. (This excluded the 11 cases of CV disease diagnosed prior to the onset of diabetes). There were no cases of CV hospitalizations for patients with type 1 diabetes.

- Of the 147 hospitalizations, 38% were in Centre hospitalier de Chibougamau, 21% in Centre hospitalier de Val-d'Or, 20% in Chisasibi Hospital, and 21% in other hospitals.
- 73% of 147 cardiovascular hospitalizations were women.

Table 4 - Number of hospitalizations of cases of type 2 diabetes for a complication of cardiovascular disease, by sex and age group, or fiscal year for the period 1995-96 to 2000-01. (n = 56)

Age group	Female	Male	Total		Fiscal year	Total	
			n	%		n	%
40 to 49	8	3	11	7.5	1995-1996	10	6.8
50 to 59	23	14	37	25.2	1996-1997	15	10.2
60 to 69	33	11	44	29.9	1997-1998	24	16.3
70 to 79	11	9	20	13.6	1998-1999	31	21.1
80 and over	33	2	35	23.8	1999-2000	34	23.1
Total	**108**	**39**	**147**	**100.0**	2000-2001	33	22.4
Percentage	**73%**	**26%**			**Total**	**147**	**100.0**

Source: MED-ECHO.

Table 5 - Average interval between the diagnosis of diabetes and the initial hospitalization for a complication of cardiovascular disease, by age group, period 1995-96 to 2000-01.

Age group	Average duration of diabetes (years)	Number of cases*
40 to 49	9.5	7
50 to 59	9.6	20
60 to 69	1.8	10
70 to 79	7.0	9
80 and over	1.2	8
Total	**10.3**	**54**

3.3 Hospitalizations for lower leg amputations

The study documented 5 cases of lower leg amputation (including toes) in patients with type 2 diabetes requiring 7 hospitalizations in the period of 1995-96 to 2000-01. 4 hospitalizations were for women and 3 for men. On average, these people had been diagnosed with diabetes 18 years before the first amputation.

3.4 Hospitalizations for renal failure and dialysis

The study identified 34 cases (3.6% of all people with diabetes) of hospitalizations for renal failure or dialysis for the period 1995-96 to 2000-01. Of these 34 cases, 9 were for dialysis.

On average, people had been diagnosed with diabetes for 10.4 years before they were first admitted to hospital for renal failure or dialysis. This is much sooner than expected. In the non-Aboriginal populations, people are diagnosed with diabetes on average for 20 years before they are first diagnosed with the onset of renal disease.

The 34 cases of renal failure required 96 hospitalizations. Of the 96 hospitalizations, 62 (64%) were women, and 34 (36%) were men.

Table 6 - Average interval between the diagnosis of types 1 or type 2 diabetes and the initial hospitalization for renal failure or dialysis, by age group, period 1995-96 to 2000-01.

Age group	Average duration of diabetes (years)	Number of cases*
30 to 39	3.2	4
40 to 49	14.4	3
50 to 59	10.6	9
60 to 69	11.3	12
70 and over	11.4	6
Total	**10.4**	**34**

Source: CDIS, MED-ECHO.

3.5 Ophthalmology: retinopathy screening and complications.

3.5.1 Retinopathy screening

On average, 55% of patients with type 1 or type 2 diabetes had been screened by an ophthalmologist in the previous 2-year period (as per Canadian Diabetes Association guidelines) during the study period of 1995-96 to 2000-01. The retinopathy screening rates decreased significantly over the course of the study period. For patients who had been diagnosed for more than 5 years with diabetes, 82.5% had retinopathy screening at least once in the 5-year study period (yet 17.5% of patients with diabetes for more than 5 years had not seen an ophthalmologist even once in the 5-year study period).

Table 7 - Proportion of cases of type 1 and type 2 diabetes that had an ophthalmologist consultation in the previous two years period.

Consultation 2 yr period	Female		Male		Total	
	n	%	n	%	n	%
01-01-1996 to 1996-1997	207	65.3	128	63.7	335	61.5
1996-1997 to 1997-1998	258	64.7	164	70.1	422	66.7
1997-1998 to 1998-1999	227	50.7	140	53.6	367	51.8
1998-1999 to 1999-2000	235	46.7	132	45.1	367	46.1
1999-2000 to 2000-2001	254	46.5	151	46.6	405	46.6
All years*	**378**	**69.2**	**222**	**68.5**	**600**	**69.0**

* Proportion of cases that had at least one consultation during the period
Source: RAMQ.

The low rates of retinopathy screening are a serious concern. A small study by the medical students in the summer of 2004 showed that this was largely due to communication problems.

Efforts will be made to increase awareness of the importance of:

- retinopathy screening by an ophthalmologist (not just an optometrist),
- early detection and prevention of progression of retinopathy before any visual changes occur.

3.5.2 Retinopathy complications

In total, 25 patients (2.8% of patients with diabetes) had had laser photocoagulation or a vitrectomy, interventions used for moderate to severe diabetic retinopathy.

On average, people had been diagnosed with diabetes for 13.3 years before they required their first laser photocoagulation or vitrectomy.

Of the 67 consultations for retinopathy complications, 42 (63%) were women, and 25 (37%) were men.

Table 8 - Consultations for laser photocoagulation or vitrectomy for cases of type 1 and type 2 diabetes by age group (Jan 1, 1996 to Mar 31, 2001).

Age group	Number of consultations	Average number of consultations	Number of cases
30 to 49	24	3.4	7
50 to 59	31	3.1	10
Above age 60	12	1.5	8
Total	**67**	**2.7**	**25**

Source: RAMQ.

Table 9 - Consultations for laser photocoagulation or vitrectomy for cases of type 1 and type 2 diabetes by sex and fiscal year (Jan 1, 1996, to Mar31, 2001)

Fiscal year (April 1 – Mar 31)			Total		
	Female	Male	Number of consultations	%	Number of cases
1/1/1996 -1997 *	16	10	26	38.8	12
1997-1998	6	0	6	9.0	4
1998-1999	10	6	16	23.9	8
1999-2000	7	6	13	19.4	7
2000-2001	3	3	6	9.0	5
Total	**42**	**25**	**67**	**100.0**	**25****

* Includes Jan 1 1996 – March 31, 1997. All other years are Apr 1 – Mar 31.
** Sum of cases in greater than total due to multiple years consultations.
Source: RAMQ

4. SUMMARY OF THE EXTENT OF MAJOR COMPLICATIONS FOUND BY THIS STUDY:

Table 10 - Main complications of cases of type 1 and type 2 diabetes from the CDIS linked to the FIPA[1], by type of complication, period 1995-96 to 2000-01.

Complication	Number of cases	Proportion of all cases (n = 949)	Average duration of the disease prior to onset (in years)	Total duration of hospitalizations (days)
Hospitalization for CVD	63	6.6%	10.3	1,402
Hospitalizations for renal failure or dialysis	34	3.6%	10.4	759
Hospitalizations for amputation of a leg or toe	5	0.53%	18.1	81
Medical procedures for laser photocoagulation or vitrectomy*	25	2.8%	13.3	-

* Period 01-01-1996 to 31-3-2001.
Source: RAMQ and MED-ECHO.
[1]FIPA = Administrative file of insured persons registered with the Régie de l'assurance maladie du Québec

Conclusion

The project was the first attempt to merge a local diabetes data base developed from clinical records with the administrative data bases of the Quebec health system using an anonymous linking method. The results show that this kind of merging can enrich our understanding of diabetes in this northern region where doctors work on salary. It is not possible to obtain the information provided in this report by analyzing each of these data base systems separately. The CDIS provides a better assessment of the number of people with diabetes in Eeyou Istchee, as well as certain types of complications, such as microalbuminuria, that are picked up at the clinical level. However, information about the use of medical services and transportation for those services by people with diabetes in the region, can be only obtained through merging the CDIS with the NDSS.

We recommend that the CBHSSJB merge the data bases on an annual basis. This could be performed with the new cases of diabetes from the annual update of the CDIS, using the same anonymous methodology used in this study to ensure confidentiality of all patients within the CBHSSJB.

APPENDIX 1. FILE LINKAGE METHODOLOGY

Step 1. Receipt by the RAMQ of the Cree Diabetes Information System file (health insurance number, date of birth, sex, community of residence, type of diabetes, date of diagnosis). This file is then transferred into the informational environment of the RAMQ.

Step 2. Validation by the RAMQ of the health insurance numbers in the information system (about 1,400 individuals). A status report is produced on the number of invalid health insurance numbers.

Step 3. Substitution by the RAMQ of the health insurance number with an non-nominal unique identifier number in the informational environment of the RAMQ.

Step 4. For cases with a valid HIN, extraction by the RAMQ of all fee-for-service medical and optometric procedures, as well as hospitalizations, FIPA and eligibility data for each individual, and establishment of a record for each individual.

Step 5. Generation by the RAMQ of non-nominal files for analysis by the INSPQ.