

Comprehensive computerized diabetes registry

Serving the Cree of Eeyou Istchee (eastern James Bay)

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ABSTRACT

PROBLEM BEING ADDRESSED Diabetes is rapidly evolving as a major health concern in the Cree population of eastern James Bay (Eeyou Istchee). The Cree Board of Health and Social Services of James Bay (CBHSSJB) diabetes registry was the initial phase in the development of a comprehensive program for diabetes in this region.

OBJECTIVE OF PROGRAM The CBHSSJB diabetes registry was developed to provide a framework to track the prevalence of diabetes and the progression of diabetic complications. The database will also identify patients not receiving appropriate clinical and laboratory screening for diabetic complications, and will provide standardized clinical flow sheets for routine patient management.

MAIN COMPONENTS OF PROGRAM The CBHSSJB diabetes registry uses a system of paper registration forms and clinical flow sheets kept in the nine community clinics. Information from these sheets is entered into a computer database annually. The flow sheets serve as a guideline for appropriate management of patients with diabetes, and provide a one-page summary of relevant clinical and laboratory information.

CONCLUSIONS A diabetes registry is vital to follow the progression of diabetes and diabetic complications in the region served by the CBHSSJB. The registry system incorporates both a means for regional epidemiologic monitoring of diabetes mellitus and clinical tools for managing patients with the disease.

RÉSUMÉ

PROBLÈME À RÉGLER Le diabète devient rapidement une préoccupation majeure grandissante en ce qui concerne la santé de la population des Cris de la région orientale de la baie James (Eeyou Istchee). Le registre des cas de diabète du Conseil Cri de la santé et des services sociaux de la Baie James représentait la première étape dans l'élaboration d'un programme complet portant sur le diabète dans cette région.

OBJECTIF DU PROGRAMME L'élaboration du registre des cas de diabète du Conseil avait pour but de définir les paramètres permettant d'observer la prévalence du diabète et la progression des complications diabétiques. La base de données identifiera également les patients qui ne jouissent pas d'un dépistage approprié des complications diabétiques, tant sur le plan clinique qu'en laboratoire, et fournira des diagrammes cliniques normalisés pour la prise en charge systématique des patients.

PRINCIPALES COMPOSANTES DU PROGRAMME Le registre des cas de diabète du Conseil a recours à un ensemble de formulaires d'enregistrement et de diagrammes cliniques qui sont gardés en dossier dans neuf cliniques communautaires. Des renseignements sont tirés de cette documentation pour être entrés annuellement dans une base de données informatisée. Les diagrammes servent de lignes directrices pour la prise en charge des patients diabétiques qui s'impose, et offrent un résumé d'une page de l'information clinique et de laboratoire pertinente.

CONCLUSIONS Il est essentiel de maintenir un registre des cas de diabète pour suivre la progression du diabète et de ses complications dans la région desservie par le Conseil Cri. Les modalités du registre procurent à la fois les moyens d'exercer la surveillance épidémiologique du diabète sucré et des instruments cliniques pour la prise en charge des patients souffrant de cette maladie.

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Many studies¹⁻⁴ have documented the recent increased prevalence of type 2 diabetes among indigenous populations of North America. Before 1940, diabetes was rare in Canadian aboriginal populations.⁵ By the late 1980s, Brassard et al⁶ documented a prevalence rate of 5.2% in the Eeyou Istchee population 20 years and older diagnosed with type 2 diabetes. An unofficial follow-up survey in 1991 found that prevalence had increased to 7.1% in this same population. This increase, however, likely underestimated the true prevalence.⁷

A recent population screening survey in an Ontario Cree community established a crude prevalence of diabetes of 17.2% among people older than 10 years.⁸ Among these people, 41% had been previously undiagnosed. It is, therefore, likely that rates documented to date in Eeyou Istchee underestimate true prevalence by as much as half.

The reasons for this recent surge in the number of cases of diabetes are not entirely clear. The "thrifty gene" theory is one postulated explanation.^{9,10} This genetic trait is believed to facilitate efficient storage and metabolism of calories to permit survival with lower dietary energy requirements. Such a gene could have provided a selective survival advantage in the past for societies who had to endure periods of food scarcity. Under new environmental conditions of unlimited access to highly processed foods and a more sedentary lifestyle, this same genetic trait has predisposed this population to obesity and the development of type 2 diabetes.

Setting up the diabetes registry within the Cree Board of Health and Social Services of James Bay (CBHSSJB) has been the first stage in a larger process of developing a comprehensive regional program for prevention and control of diabetes and its complications.

Setting

The territory on the eastern side of James Bay, known to the 12 000 Cree as Eeyou Istchee, covers

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300 000 km² of sub-Arctic boreal forest—a region comparable in size to New Brunswick or France. Traditionally, the Cree were seminomadic hunters. Patterns of year-round residence began in the 1940s to 1970s in five communities along the James Bay coast and four inland communities on lakes and rivers feeding into James Bay. Today, only two coastal communities remain without permanent road access.

Health services are provided in community clinics staffed by nurses and community health representatives (CHRs). Physicians reside permanently in five communities and provide services in the other communities at intervals of 2 to 6 weeks. The 30-bed regional hospital in Chisasibi provides telephone coverage for communities when no physician is present. Turnover of nurses and doctors in the region is fairly rapid, creating challenges in providing continuity of care.

Methods

World Health Organization criteria for diagnosis of diabetes mellitus were used.¹¹ Diagnostic criteria used for the registry will be updated based on changes to the diagnostic criteria recently recommended by the Canadian Diabetes Association¹² and American Diabetes Association.¹³

The registry consists of two types of data-collection forms kept in each clinic: a registration form and flow sheets. All forms used are forwarded to a central site for data entry annually.

The registration form (**Figure 1**) contains basic information on each patient: Quebec health card number (RAMQ), chart number, band number, date of birth, sex, height, type of diabetes, and date of onset. The RAMQ is used as the unique identifier for each case. Each form provides space for 20 new cases. A change in the type of diabetes (ie, impaired glucose tolerance becomes type 2 diabetes mellitus) is considered a new case. Deaths of patients with diabetes are registered on the same form. Cause of death and date of death are recorded.

There are two types of flow sheets: one sheet for patients with type 1 or type 2 diabetes and a second for patients with impaired glucose tolerance or previous gestational diabetes mellitus. The flow sheet for patients with type 1 or type 2 diabetes (**Figure 2**) was developed so that each section could provide a concise yet complete summary of relevant clinical and laboratory information concerning each patient over a 3- to 5-year period. All microvascular and

macrovascular complications are noted on this flow sheet. As well, each microvascular complication is divided into grades of severity to follow the progression of the specific complication. For example, diabetic nephropathy is divided into stages of microalbuminuria, macroalbuminuria, renal failure, and dialysis. Only complications related to diabetes are recorded. To standardize the diagnostic criteria for each complication, a comprehensive manual that includes clear definitions for each complication is available in every clinic.

A second flow sheet was developed to follow patients with impaired glucose tolerance and previous gestational diabetes (Figure 3). Monitoring this population will provide data on the rate of progression of these conditions to type 2 diabetes. It will also ensure regular screening among people at high risk for diabetes who are in danger of being lost to medical follow up. Because risk of

macrovascular disease is doubled among patients with impaired glucose tolerance,¹⁴ a section on macrovascular complications and lipid screening is included. Flow sheets are not designed for antenatal management of patients with gestational diabetes.

A computerized database was established using the Omnis7 software on a Macintosh personal computer. The database includes all information on the registration form and the two flow sheets. Computer screens presents information in a user-friendly manner identical in appearance to the flow sheets.

A comprehensive handbook was provided in each clinic explaining how the registry functioned and the roles of various health care providers. It also included definitions used for diagnosing type 1 and type 2 diabetes, impaired glucose tolerance, gestational diabetes mellitus, and diabetic complications.

Figure 2. Abridged flow sheet for impaired glucose tolerance and previous gestational diabetes mellitus

Abridged Flow Sheet for IGT and previous GDM

RAMO Number: _____ **Chart Number:** _____

Community: _____

General

Type of Diabetes	_____
Date of Diagnosis	_____

Annual MD visit

Date (yr/m/d)	BP mmHg	Weight (Kg)	Actvty (1-5)	Smoker (Y/N)

Diabetes screening

Date (yr/m/d)	AC Glu (mmol/L)

Lipids

Date (yr/m/d)	Chol mmol/L	HDL mmol/L	LDL mmol/L	Trigl mmol/L

Macrovascular complications

	Date of onset
CAD	
CVD	
PVD	

Figure 3. Abridged diabetes registration form

Abridged CBHSSJB Diabetes Registration Form

Community: _____
 Year ended: Dec 31, _____

For new cases or a change in type of diabetes

RAMQ Number	Chart #	Band #	Sex	Ht (cm)	Dqte of birth	Type *	Date of Dx	Consent
								obtained refused
								obtained refused
								obtained refused

*Type: T1=Type I DM, TII=Type II DM, GDM=Gestational DM, IGT=Impaired Glu Tolerance

Deaths

RAMQ Number	Chart Number	Date of Death	Cause of Death

After sending a letter introducing the registry to the chiefs of each community, a radio campaign was used to generate public interest and support for the project. A one-page description of the project in both English and Cree is available for general distribution. Annual reports in both English and Cree were distributed to all the chiefs, band councils, clinics, and local media to generate continued support for the project and increase awareness of the magnitude of diabetes in the communities.

Initial chart review and data entry was done during the summer of 1996. Cases were identified by reviewing each clinic's list of patients with known chronic medical conditions. Cases of gestational diabetes were included only if the diagnosis had been made after January 1, 1996. After this initial chart review, flow sheets and registration forms were updated by the treating physicians and nurses. New cases were identified and registered by local health care workers.

Consent and confidentiality

Consent was obtained from all patients who agreed to participate in the registry. This was done so that confidential clinical and laboratory information from the patients' charts could be transferred to a central registry.^{15,16} Whenever possible, the Cree-speaking CHR explained how the registry functioned and discussed the issue of consent with patients. Final approval for the project and consent form was granted by a local ethics review committee consisting of several Cree members of the CBHSSJB Board of Directors.

Patients who did not consent to participate were still recorded on the central computer registry as a "case," and the basic epidemiologic data found on the registration form were entered. Their flow sheets continued to be used as a clinical tool to optimize their management, but no information from these sheets was transferred to the central registry. All patients were informed of this arrangement. Patients

were also aware that their RAMQ was used as a unique identifier.

Access to information in the registry was available only through written request to the registry coordinator. Final authorization was at the discretion of the CBHSSJB Board of Directors.

Evaluation

The staff of each clinic was encouraged to recommend ways to improve registry function. The registry process will be evaluated annually for 2 years and biennially thereafter. The evaluations consist of 10-minute interviews with the nurses, physicians, and CHRs in each of the nine communities. A form for anonymous written feedback is available in each clinic.

Annual audits of a percentage of each clinic's flow sheets ensure that the information is accurate and up-to-date. The computer program has built-in safeguards to disallow duplicate entries of the same patient and will not accept laboratory values outside a reasonable range.

Data will be analyzed in 3 to 5 years for publication in the medical literature. This time will be required to ensure accuracy and validity of the data available for analysis.

Discussion

Several other diabetes registries have been described in the literature.¹⁷⁻²¹ Most are simply databases that record epidemiologic information. The registry from Howitt and Cheales¹⁷ of southeast England is a cross-sectional survey that provides information on prevalence of diabetes, related epidemiologic factors, metabolic control, and diabetic complications. The registry from Johnson and Straus¹⁸ is a survey of diabetes cases among the Mississippi Choctaw Indians that also provides information on point prevalence. A similar registry designed by Martinez and Straus¹⁹ for a Mohawk community establishes the point prevalence of diabetes, shows the incidence of diabetic complications, and identifies risk factors for development of this disease.

The CBHSSJB registry differs from these registries in several ways. Our registry is fully computerized and includes information for the entire Cree territory of eastern James Bay—nine separate communities. Like the other registries described, it records all epidemiologic information on patients with diabetes to allow measurements of both point prevalence and incidence of the disease and its complications. Because it is an ongoing project and not

Key points

- In this area, the continuity of care needed for diabetes is challenged by high turnover of medical personnel. This challenge was met by devising a registry comprising a registration form (used for epidemiologic purposes) and flow sheets guiding follow-up assessment. The flow sheets are further stratified for patients with type 1 or type 2 diabetes and those with impaired glucose tolerance (IGT) or gestational diabetes mellitus (GDM).
- The registry combines epidemiologic surveillance and practice audit. It aims to improve quality of care and to collect population-specific data to support health care planning at the community level.

simply a cross-sectional survey, it can identify trends in metabolic control for any given patient, as well as for patients who are becoming lost to follow up. The database is accessed to signal when patients have poor glycemic control or are receiving inadequate monitoring (no microalbuminuria screen or physician follow up for 1 year, no ophthalmologic examination for 2 years, etc).

Unlike the other registries, the CBHSSJB registry incorporates clinical flow sheets and a comprehensive management guideline developed expressly for use throughout the territory to standardize and optimize the clinical care of patients. Finally, because the registry follows patients with impaired glucose tolerance and gestational diabetes, it provides information on the rate of progression of these conditions to frank type 2 diabetes.

The registry described will have several secondary benefits. It will provide the regional health board with the necessary epidemiologic framework to follow trends in rates of diabetes and diabetic complications in order to improve regional health planning. It will also provide a database for future research on diabetes in the region.

Development and maintenance of a comprehensive diabetes registry is a labour-intensive process. Analytic power of the registry is improved as more information is added to the database. This increasing complexity, however, increases the risk of noncompliance and error. The goal in developing flow sheets was to include enough relevant information to ensure epidemiologic and clinical value, while preserving the simplicity necessary to encourage ongoing clinical use.

Long-term maintenance of this complex registry requires a financial commitment by the regional

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health board (CBHSSJB). For the Cree Health Board, this will be incorporated into a global budget for diabetes in the region.

Conclusion

Diabetes is rapidly becoming an important health concern among the Cree of Eeyou Istchee. Accurate documentation of the magnitude of the problem is necessary before designing a comprehensive regional health plan. A central registry that includes information on rates of diabetes, associated complications, and laboratory values will allow monitoring of the progression of diabetes and management trends in the region. This project will provide the framework for improving many areas of diabetes care both locally and regionally. ❖

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