THE CURRENT STATUS OF DIABETES CARE, DIABETIC RETINOPATHY SCREENING AND EYE-CARE IN BRITISH COLUMBIA’S FIRST NATIONS COMMUNITIES

ABSTRACT

Objectives. The objective of this study was to evaluate the current status of primary diabetes care, diabetic retinopathy screening, and eye-care for First Nations individuals with diabetes living on-reserve in British Columbia.

Study Design. Prospective cross-sectional observational survey.

Methods. A mail-out survey was sent to all BC First Nations Communities in the format of a 26-item questionnaire. A series of general questions were asked concerning community populations, regional transportation options and the availability of local health-care providers. Specific questions about the frequency and source of eye and diabetic retinopathy care in each community were also solicited.

Results. A sixty-seven percent questionnaire response rate was achieved (136/202 communities). The community-reported rate of diabetes mellitus ranged from 4.8 to 11.8% with an average of 6.4%. The proportion of on-reserve individuals with diabetes receiving yearly retinal examinations for diabetic retinopathy was found to be only 33%. Many communities received eye-care from more than one professional group, but the majority of basic eye-care and retinopathy screening was provided by optometrists. Ophthalmologists were less likely to provide eye care for these communities; however, family physicians and nurses were frequently responsible for performing eye evaluations.

Conclusions. The vast majority of First Nations people with diabetes who live on-reserve in British Columbia do not have access to annual examinations by an eye-care professional. Eye evaluations and retinal screening were often the responsibility of individuals with little formal training in this area. (Int J Circumpolar Health 2004;63(3):277-285)

Key Words: First Nations, diabetes, diabetic retinopathy, screening
INTRODUCTION

The prevalence of diabetes in Canadian First Nations (FN) peoples ranges from 5 – 10% (1) and can be as much as two to four times higher than that of the general Canadian population (estimated at approximately 2.5%) (2,3). In particular Canadian FN communities, age-adjusted diabetes prevalence figures of between 19% and 26% have been reported (4,5).

Diabetic retinopathy is the leading cause of blindness in working-age individuals in Canada (6). As with diabetes, the prevalence of diabetic retinopathy appears to be elevated in aboriginal communities (7,8). Screening for diabetic retinopathy has been shown to decrease the risk of vision loss (9), making diabetic retinopathy a preventable cause of blindness in Canada. However, many patients with diabetes do not attend recommended annual (10), or biannual examinations by an eye-care professional (11).

First Nations populations, in general, have less access to health-care services than other Canadians, frequently because of geographic isolation. Thirty (30%) to 50% of Canadian aboriginal communities are in remote regions, many accessible only by air (12). Furthermore, a shortage of personnel trained to meet the cultural and medical needs of particular bands also limit health-care in these communities. Supplementary regional and community-specific health data is needed to assist in the development of programs to target particular health problems, such as the detection and management of diabetic retinopathy. The purpose of this paper was to evaluate the current status of diabetes care, basic eye-care and diabetic retinopathy screening in British Columbia’s First Nations population living on-reserve.

METHODS

A mail-out survey was sent to all First Nations communities in British Columbia. A 26-item questionnaire was developed via a collaborative process involving the National Coordinator of Aboriginal and Inuit Services for the Canadian National Institute for the Blind (CNIB) and the University of British Columbia’s Department of Ophthalmology.
A list of First Nations communities in British Columbia was obtained from the Assembly of First Nations, the national representative organization. The questionnaires were addressed to the Community Health Representatives (CHR) and the Chiefs of the respective bands. In communities without CHRs, a health worker proxy was asked to complete the questionnaire.

The questionnaire included queries about community size, community accessibility (road, air, water), the prevalence of diabetes, barriers to diabetes care (providers & accessibility), barriers to primary and secondary eye-care, and diabetic retinopathy care (providers & accessibility).

A total of 202 questionnaires were mailed out in June 2001. To maximize the response rate, phone calls were made to non-respondents four weeks after the initial mailing and another copy of the questionnaire was faxed to the CHRs and Chiefs. Responses were accepted until September 15, 2001.

RESULTS

The First Nations communities surveyed were organized into six districts according to the Aboriginal Health Council Regions used by the Aboriginal Health Association of British Columbia (13). These areas included the Lower Mainland, Fraser Valley, Vancouver Island and Central Coast, Thompson-Okanagan-Kootenay, North-East and North-West (Figure1).

Information reported on questionnaires included data for each community as a whole. No individuals were to be identified by any of the questions in the questionnaire. In addition, the confidentiality of bands was ensured by analyzing the questionnaires as grouped data, organized by the regions described above. Ethical approval was received from the University of British Columbia Institutional Review Board prior to commencing this study.

Overall, a response rate of 67% (136/202) was achieved. Community health representatives (CHRs) completed 56% of the surveys, community health nurses (CHNs) completed 34%, and other staff members of health centres, or band administrative offices (community health workers, social workers), completed 11% of the questionnaires.
Results summarizing questionnaire response rates, community-reported diabetes prevalence figures, and the accessibility of primary diabetes care are shown in Table I. Approximately 50% of all communities receive general diabetes health services on-reserve. The community-reported rate of diabetes ranged from 4.8 to 11.8%, with a provincial average of 6.4%. We observed no geographic gradient in diabetes prevalence as has been found in other studies (1).

The providers of regular eye-care and the proportion of First Nations people with diabetes who receive yearly retinal examinations are noted in Table II. The average proportion of FN people in BC with diabetes receiving yearly retinal examinations was found to be only 33%. In the North-West region a yearly retinal screening rate of 70% was noted, nearly double the provincial average. Of note, the rates in the relatively developed regions of the Lower Mainland and the Fraser Valley were only 32% and 24%, respectively.

Figure 1. Six Health Regions of BC First Nations Communities, as organized by the Aboriginal Health Association of BC. 1. Lower Mainland; 2. Fraser Valley; 3. Thompson-Okanagan-Kootenay; 4. Vancouver Island & Central Coast; 5. North-East; 6. North-West.
In BC, the majority of basic eye-care for First Nations people living on-reserve is being provided by optometrists, with 108 out of 136 communities receiving care from this professional group. Ophthalmologists are providing regular eye-care to 42 communities, and GPs, or nurses, were reported to be providing basic eye-care for 40 bands. The same trends were observed for the provision of diabetic eye-care (namely retinal screening) on-reserve – 81/136 of the communities are screened by optometrists, 50/136 by ophthalmologists and 38/136 by GPs or nurses. Many communities are receiving care from more than one type of provider, resulting in proportions in Table II that add up to more than 100%.

| Table I. General Diabetes Care On-Reserve. |
|--------------------------------------------|
| Region | Community-reported prevalence of DM (%) | Proportion of DM-care provided on-reserve (%) |
|--------|------------------------------------------|---------------------------------------------|
| North-West | 4.5 | 50 |
| North-East | 6.0 | 55 |
| Thompson-Okanagan-Kootenay | 4.8 | 34 |
| Vancouver Island & Central Coast | 7.8 | 61 |
| Fraser Valley | 6.5 | 45 |
| Lower Mainland | 11.8 | 38 |
| **TOTAL** | **6.4** | **49** |

| Table II. Provision of eye-care in BC First Nations communities. |
|---------------------------------------------------------------|
| Region | Providers of regular eye-care | Proportion of diabetics receiving yearly retinal examinations | Providers of retinal examinations |
|--------|------------------------------|-------------------------------------------------|---------------------------------|
|        | GP* or Nurse | Optometrist | Ophthalmologist | GP* or Nurse | Optometrist | Ophthalmologist |
| North-West | 5/17 | 9/17 | 11/17 | 70 | 4/17 | 10/17 | 8/17 |
| North-East | 13/31 | 26/31 | 3/31 | 36 | 12/31 | 18/31 | 7/31 |
| Thompson-Okanagan-Kootenay | 12/35 | 30/35 | 14/35 | 24 | 10/35 | 17/35 | 18/35 |
| Vancouver Island & Central Coast | 7/34 | 26/34 | 7/34 | 26 | 5/34 | 17/34 | 7/34 |
| Fraser Valley | 3/11 | 8/11 | 3/11 | 24 | 4/11 | 8/11 | 3/11 |
| Lower Mainland | 0/8 | 7/8 | 3/8 | 32 | 0/8 | 6/8 | 3/8 |
| **TOTAL** | **40/136** | **106/136** | **4/136** | **33** | **35/136** | **76/136** | **46/136** |

* GP: General Practitioner, or Family Physician

Note: Some communities have eye services provided by more than one category of care provider.
DISCUSSION

The use of questionnaires in community-based surveys has certain limitations. One is the inherent bias in the selection of questions and in the choice of respondents. Our questions were developed in conjunction with the National Coordinator of Aboriginal and Inuit Services of the CNIB. They were chosen to balance ease of administration with a need to obtain detailed information about health-care and barriers to care in these communities. We chose to distribute the questionnaires to on-reserve community health representatives (CHRs), since they are responsible for much of the health-care administration in these communities. We were not particularly concerned about situations where community health nurses (CHNs) served as proxies for CHRs (34%), since it is often the CHNs who would have direct access to the information we requested.

The main difficulty with the administration of any survey is the response rate. A recent study evaluating diabetes care in British Columbia received responses from only 37% of surveyed First Nations communities (14). We were able to obtain an excellent response rate of 67%. Only 67 out of 202 communities did not reply. Many of the non-responders may not have received questionnaires, as we were unable to establish phone, fax, or mail contact with 32 of the 67 non-responding CHRs. This is still a large enough proportion of the total that our results are likely to be somewhat affected by volunteer bias.

Participation/non-participation in this study may have been affected by issues related to diabetes and diabetes care; however, with questionnaire-based studies, it is not possible to know whether this was the case. If prevalence of diabetes, or access to diabetes care, influenced participation in our survey, our results may mis-represent the state of diabetes and eye-care in our province. For example, communities with severe diabetes care problems may have been unwilling to document this issue for a third party (the regional university).

In the national diabetes survey by Young et al. (1), BC was found to have one of the lowest prevalence rates of diabetes in Canada (1.6%). The 1995 survey conducted by Martin and Yidegiligne found an overall diabetes rate of 2.2% (15). In our
survey, we found an overall community-reported rate of diabetes of 6.4%. To arrive at this figure, our survey asked for community populations, as well as the number of individuals with diabetes in each community. One limitation of these particular prevalence results is that there was no validation of the methodology used by each community to determine a diagnosis of diabetes. In addition, some communities did not provide an actual number of patients with diabetes, but reported a range. This could have led to an inflated estimate of diabetes prevalence in this study; however, our results do fit with those of Young and Martin and do suggest a trend towards an increasing prevalence of diabetes in BC since 1990. This finding would certainly fit with an increasing westernization of First Nations’ diets and the ongoing erosion of traditional ways of living.

With an increasing prevalence of diabetes in First Nations communities in BC, complications of diabetes are likely to increase as well. Ross et al. studied First Nations people with diabetes in Alberta, and found that insulin-using Aboriginal people with diabetes suffer from more severe retinopathy than insulin-using non-Aboriginal people with diabetes (16). A high proportion of BC’s Aboriginal people with diabetes, 39.6%, have been found to be insulin-dependent (14). Practice guidelines for the care of patients with diabetes in Canada recommend annual diabetic retinopathy screening of this particular group of high-risk diabetes patients (17).

Our study has shown that the vast majority (97%) of BC First Nations on-reserve diabetes patients are not receiving annual examinations by an ophthalmologist. Even in communities where individuals with diabetes were receiving yearly retinal examinations, 26% of those examinations were being provided by family physicians, or nurses. This has significant implications, as Sussman and colleagues have demonstrated higher error rates in the evaluation of diabetic retinopathy by non-ophthalmologists. They found sensitivities (for disease detection) of 27% for internists, 31% for senior medical residents, 36% for diabetologists (18), under ideal conditions with pupils fully dilated.

The ability to correctly diagnose diabetic retinopathy may be further reduced with an undilated retinal examination. Unfortunately, we cannot assume that optometrists, family physicians, or
nurses working with First Nations communities are uniformly conducting dilated examinations. As a result, we believe it is essential to establish effective diabetic retinopathy screening programs for communities without ophthalmic care.

First Nations communities in BC are unique. In comparison to the rest of Canada, where a history of displacement to reservations predominates, almost all pre-existing First Nations villages in BC (except for the North-East) were designated reserves in the early 1900s. By the completion of this allocation in 1916, there were 231 recognized bands in BC allotted some 1900 reserves (19). This has resulted in approximately 200 distinct First Nations communities in BC, with an average band size of 250. In comparison, Quebec has a total of 39 reserves with an average size of approximately 1000. Given the rugged geography of BC, smaller and more isolated bands are particularly at risk for not receiving adequate health-care. Of the 136 communities that responded to our survey, 17 reported not being accessible by road (accessed by plane, helicopter, boat only).

There are numerous options to increase screening rates in isolated communities. Increasing optometrist and ophthalmologist travel to isolated regions, or transporting diabetes patients to urban areas, for yearly examinations are both very costly options. Digital retinal cameras operated by technicians in remote areas are one alternative. Images are sent electronically to tertiary centres for appropriate diagnosis and triage by a retina specialist. Cost assessments have demonstrated that a mobile retinal camera screening program can provide screening care at a cost advantage over existing care paradigms (8,15). It is expected that the recent establishment of such a program in BC will be invaluable for increasing the access of isolated First Nations communities to screening services and a better level of ocular health.
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