Monitoring Disease Burden and Preventive Behavior With Data Linkage: Cervical Cancer Among Aboriginal People in Manitoba, Canada

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ABSTRACT

Objectives. This study sought to estimate rates of cervical cancer and Papanicolaou testing among Aboriginal and non-Aboriginal women in Manitoba, Canada.

Methods. Data were derived through linking of administrative databases.

Results. In comparison with non-Aboriginal women, Aboriginal women had 1.8 and 3.6 times the age-standardized incidence rates of in situ and invasive cervical cancer, respectively. With the exception of those aged 15 to 19 years, Aboriginal women were less likely to have had at least 1 Papanicolaou test in the preceding 3 years.

Conclusions. Data linkage provides a rapid and inexpensive means to estimate disease burden and preventive behavior in the absence of registries. There is an urgent need for an organized Papanicolaou test screening program in the Aboriginal population. (*Am J Public Health.* 2000;90:1466–1468)

Aboriginal/Native American women in Canada and the United States have been shown to be at higher risk for developing and dying from cancer of the cervix than the general population.[1–5] Cervical cancer is considered a "modern" cancer in these populations, the result of rapid social and lifestyle changes.[6] Despite the existence of effective secondary preventive measures, studies have shown that this high-risk population is less likely than lower risk groups to participate in Papanicolaou (Pap) test screening programs.[7,8]

Effective cancer control programs for Aboriginal women in Canada are hampered by the lack of a cancer registry that collects information on ethnic group and by the exclusion of Indian reserves from coverage in national health surveys in which preventive health practices are periodically monitored. In this study, existing administrative databases were linked to provide estimates of both the burden of cervical cancer and the extent of Papanicolaou testing among Aboriginal women in the province of Manitoba, Canada.

Methods

The provincial department of health in Manitoba administers the Manitoba Health Services Insurance Plan, which covers all residents of the province for physician and hospital care and reimburses service providers on the basis of claims submitted. The plan maintains and updates a claims database with information on services provided, along with a population registry that contains dates of enrollment and cancellation of coverage. The database has been used extensively in health services and epidemiologic research, and considerable efforts have been made to establish its quality and accuracy.[9] Inclusion of beneficiaries' addresses allows both cases and denominator populations to be attributed to regional health authorities. For this study, regional health authorities in the province were grouped in the following categories: (1) Winnipeg, (2) south–rural; and (3) north–remote.

In this report, the term *Aboriginal* is used to refer only to First Nations people who are registered with the Department of Indian and Northern Affairs under the Indian Act. The Manitoba Health Services Insurance Plan population registry does not contain information on race or ethnic group, but it is possible to identify registered members of First Nations (Indian reserves).

Overall, the Aboriginal population is younger than the non-Aboriginal population, and thus rates and proportions were age standardized by the direct method when appropriate. The total 1991 Manitoba population (both Aboriginal and non-Aboriginal) was used as the standard.

The Manitoba Cancer Registry, which has been in existence since 1937 and has been pop-

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This brief was accepted February 17, 2000.

TABLE 1—Incidence of Cervical Cancer and Frequency of Pap Tests Among Women in Manitoba, Canada: 1984–1997

	Incidence of In Situ Cancer (per 100 000)		Incidence of Invasive Cancer (per 100 000)		Prevalence of Pap Testing, %	
	Aboriginal Women	Non-Aboriginal Women	Aboriginal Women	Non-Aboriginal Women	Aboriginal Women	Non-Aboriginal Women
Age-specific rate						
15–19, y	71.2	25.6	0.0	0.2	51.7	38.8
20–34, y	269.4	158.0	29.1	7.9	64.5	75.2
35–64, y	102.9	57.7	48.2	14.9	42.8	65.6
>65, y	44.7	13.3	74.5	18.1	10.3	33.1
Total	102.5	60.6	19.5	9.7	52.7	60.2
Age-standardized rate						
Winnipeg	127.5	63.4	45.2	10.0	56.3	62.8
South–rural	93.8	69.2	24.8	12.4	47.1	57.7
North–remote	119.4	52.8	41.3	8.3	33.0	56.2
Total	110.1	60.3	34.1	9.5	42.6	60.4

Note. Incidence data cover the period 1984–1997; Pap test prevalence covers the period from fiscal years 1993–1994 to 1995–1996.

ulation based since 1956, does not contain information on ethnic backgrounds. To determine First Nation status, we linked cancer registry records to the Manitoba Health Services Insurance Plan population registry. All incident cases of malignant (*International Classification of Diseases, 9th Revision* [*ICD-9*] code 180) and in situ (*ICD-9* code 2331) cervical cancer occurring in the years 1984 to 1997 were extracted from the linked databases.

There is no population-based Papanicolaou test registry in Manitoba, but we were able to identify, from the Manitoba Health Services Insurance Plan databases, all women whose physicians had submitted claims for performing Papanicolaou tests by using the method initially developed by Cohen and Hammerstrand.[10] Also, we used as a criterion the recommendation of the 1989 National Workshop on Screening for Cancer of the Cervix that women be screened once every 3 years from the age at sexual debut to the age of 69 years.[11] We therefore established a cohort of women who were continuously resident in the province for a 3-year period during fiscal years 1993–1994 to 1995–1996 and determined the number of Papanicolaou tests each woman received within that period.

Results

In comparison with non-Aboriginal women, Aboriginal women had 1.8 and 3.6 times the age-standardized incidence rates of in situ and invasive cervical cancer, respectively. The Aboriginal rate was higher than the non-Aboriginal rate in all age groups and all 3 regions. The age-specific pattern differed between in situ and invasive cancer, with a peak incidence in the 20- to 34-year age group for in situ cancer; for invasive cancer, there was a linear relationship between age and incidence (Table 1).

With the exception of those aged 15 to 19 years, Aboriginal women were less likely to have had at least 1 Papanicolaou test in the preceding 3 years than non-Aboriginal women. When rates were standardized for age, results showed that 43% of Aboriginal women received 1 or more tests, as compared with 60% of non-Aboriginal women (Table 1). Within each region, the non-Aboriginal proportion exceeded the Aboriginal proportion.

Discussion

This study supports existing data on the higher risk of cervical cancer among Canadian Aboriginal women and their lower rate of Papanicolaou testing. The method used here of linking databases—the provincial cancer registry, the population registry, and the health insurance claims database—allowed rapid determination of disease burden and participation in preventive health services. Such data can be used in the planning and evaluation of cancer prevention programs and are particularly useful in the absence of a population-based Papanicolaou test registry and as an alternative to periodic interview surveys of samples of the population.

The current system of Papanicolaou test screening in Manitoba can be described as opportunistic, although the provincial government has recently provided funds for an organized provincewide screening program to ensure that those women who have never been screened or have been infrequently screened are targeted for recruitment. The need for such a program among the Aboriginal population is especially urgent.

One approach to reducing the burden of cervical cancer is through primary prevention directed at reducing the rate of infection and transmission of the human papillomavirus, especially among adolescents and young adults. Limited data on Canadian Aboriginal women indicate that the prevalence of human papillomavirus is not significantly different from that among non-Aboriginal women, although Aboriginal women report higher levels of sexual activity in terms of various indicators such as age at onset, number of lifetime sexual partners and partners in the previous year, and frequency of sexual intercourse.[12]

Despite the effectiveness of Papanicolaou test screening, high-risk groups such as Aboriginal women are not participating as frequently as lower risk groups. Such nonparticipation is not only the result of lack of information; it is also due to cultural and gender-related factors.[13–15] Beyond the clinical, technical, financial, and organizational proficiency required of Papanicolaou test screening programs, essential elements are an awareness and understanding of cultural concepts of cancer and its prevention and sensitivity to cultural barriers. ☐

Contributors

T. K. Young, E. Kliewer, and J. Blanchard jointly planned the study. E. Kliewer extracted and analyzed the cancer incidence data from the Manitoba Cancer Registry, and J. Blanchard extracted and analyzed the Papanicolaou test prevalence data from the Manitoba health database. T. K. Young wrote the paper, which was revised and approved by all coauthors. T. Mayer performed the literature search and assisted in data management and analysis.

Acknowledgments

Funding for this study was provided by a contract from the First Nations and Inuit Health Programs, Medical Services Branch, Health Canada.

We acknowledge Dr Linda Bartlett and Nicholas Trudel of the Medical Services Branch for their helpful comments during the course of the study.

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