

A VITAL STATISTICS SYSTEM FOR DETERMINING BIRTHS AND MORTALITY IN THE FIRST NATIONS POPULATION OF BRITISH COLUMBIA, CANADA

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ABSTRACT

We describe a unique method for producing province-wide and selected regional birth and death statistics for the First Nations population. We identified births and deaths of persons with Indian Status in the province of British Columbia, Canada, using three databases: the Vital Statistics Agency's database of births and deaths, the Department of Indian Affairs' Indian Status Verification File and the provincial health insurance plan's Status Indian Entitlement file. A birth or death was considered Status Indian if the person was so identified in any of the three sources. From 1991 through 1998, 24,159 live births were identified as Status Indian: 54% by all three sources, 29% by two sources and 17% by one source. In the same period, 5,680 Status Indian deaths were identified: 28% by all three sources, 38% by two sources and 34% by one source. Deaths were grouped by Underlying Cause and rates in each category were age-standardized for comparison to the general population. This project underscores the importance of using more than one database to ensure complete counting. Otherwise, birth and death rates will be underestimated. This has implications for national reporting if each province does not have a comparable system. (*Int J Circumpolar Health* 61; 2: 92- 97)

Keywords: Aboriginal, North American Indian, First Nations, Canada, British Columbia, Vital statistics

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Until the early 1980s, the compilation of vital statistics data for the Status Indian population of British Columbia, Canada was done by the Pacific Region of the Medical Services Branch (since renamed as the First Nations and Inuit Health Branch) of Health Canada. Certificates of Birth and of Death were made available by the Vital Statistics Agency of the British Columbia Ministry of Health to the federal Department of Indian Affairs and Northern Development ("Indian and Northern Affairs Canada") for updating of their Status Verification Files. In turn, Indian and Northern Affairs Canada would make these Certificates available to Medical

Services Branch of Health Canada with the names blanked out. Each Certificate had a box to check if the recorder believed the newborn or the deceased to be Status Indian. Thus, only Certificates with this box checked would be entered into this database. In the mid 1980s, new federal and provincial legislation regarding privacy were introduced. Indian and Northern Affairs Canada interpreted this to mean that information of this kind could not be shared and Medical Services Branch was no longer given these certificates for compilation of birth and death reports. Thus, Pacific Region was unable to report from about 1982 until 1991 when a new system of reporting was developed.

With the restructuring of the provincial Vital Statistics Agency in the late 1980s and the development of a special research unit in that agency it was possible to work together in the development of a state-of-the-art birth and death reporting system. The Medical Services Branch contracted with the Vital Statistics Agency for the development of a system for annual reporting of birth and death statistics for the Status Indian population of British Columbia and arranged for the purchase of a sophisticated software system for use by the agency for the matching of Status Indian registers against the total number of deaths from all causes for the entire population of the province. Births were matched in the same way. Under this contractual arrangement, the Status Verification File of Indian and Northern Affairs Canada could only be used for the specific purpose of producing these birth and death reports. The process of getting approvals and setting up the system took about one and a half years from inception. The first report was produced in 1991.

METHODOLOGY

This project uses a unique methodology to identify the Status Indian births and deaths in British Columbia and to produce provincial and regional Status Indian population estimates.

Status Indian people (i.e., persons recognized as having Indian Status as defined by the Indian Act of Canada) are one part of the broad group of Aboriginal people in British Columbia. There is considerable interest in the health status of Aboriginal peoples, whether Status Indian, "non-Status Indian" (i.e., persons of North American Indian ethnicity who



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do not qualify for Indian Status), Métis or Inuit. In British Columbia, relevant data exist only for Status Indian people. The sources used to identify Status Indian births and deaths were the British Columbia Vital Statistics Agency, the Medical Services Plan of British Columbia (the province's universal health insurance program) and Indian and Northern Affairs Canada. Status Indian people were the only Aboriginal group that could be identified from these sources.

Using this information, annual reports are produced that list the birth-related and mortality statistics for the combined Status Indian population resident on- and off-reserve. These are compared to all other British Columbia residents. The major sources of data were the British Columbia Vital Statistics Agency's statistical database ("VS") of information extracted from the registration of births and deaths, including demographic information, medical information related to the birth or cause of death and whether or not the individual had Indian Status. In addition, two other data bases were used to identify Status Indian persons who were resident in the province: the Indian Status Verification File ("SVF") maintained by Indian and Northern Affairs Canada and the Medical Services Plan of British Columbia's Status Indian Entitlement file ("MSP") which lists Status Indian people who have registered to have their premiums paid by Health Canada. (Only two provinces in Canada, British Columbia and Alberta, require registrants in their health insurance programs to pay premiums. In order to maintain a uniform standard of access to physician and hospital services for Status Indian people across Canada, the federal government pays the premiums for Status Indian people in these two provinces). Using a sophisticated computer matching process, a birth or death in the VS database was considered to be a Status Indian event if the individual was identified as Status Indian in any of the three sources.

Using a combination of the VS, MSP and SVF files, 24,159 live births in the eight year period 1991-1998 were identified as Status Indian events (see Table I). More than half (53.6%) of all births were identified by all three sources, another third (29.5%) were identified by two sources and the remaining 17.0% were identified by only one of the three sources.

Using a combination of the VS, MSP and SVF files, 5,680 deaths in the eight year period 1991-1998 were identified as Status Indian events (see Table II). More than a quarter (27.8%) were identified as Status Indian in all three data

Table I. Number of Status Indian Live Births Identified by Source, British Columbia, 1991-1998

Source	Year of Birth								Total 1991-98	
	1991	1992	1993	1994	1995	1996	1997	1998	No.	%
VS only	142	122	173	218	245	270	334	360	1864	7.7
MSP only	191	45	38	36	49	40	22	56	477	2.0
SVF only	360	366	268	184	120	105	118	253	1774	7.3
MSP & SVF	1136	1188	1127	522	403	384	336	218	5314	22.0
VS & SVF	59	76	163	177	216	183	370	363	1607	6.7
VS & MSP	16	12	4	18	17	35	41	40	183	0.8
VS, MSP, SVF	1122	1176	1219	1914	2005	2087	1669	1748	12940	53.6
Total	3026	2985	2992	3069	3055	3104	2890	3038	24159	100

Notes: VS indicates that the event was identified by the BC Vital Statistics Agency.
MSP indicates that the event was identified by the Medical Services Plan of BC
SVF indicates that the event was identified by the Indian Status Verification File.

sources, two fifths (38.0%) were identified in two and the remaining third (34.2%) by only one source.

By definition, every Status Indian newborn or deceased person should be found in all three data bases. For birth statistics, there are reasonable explanations for the proportion which are found in only one or two databases. Status Indian parents need to apply for an Indian Status registration number for their child and need to register their child for coverage by the Medical Services Plan of British Colum-

Table II. Number of Status Indian Deaths Identified by Source, British Columbia, 1991-1998.

Source	Year of Death								Total 1991-98	
	1991	1992	1993	1994	1995	1996	1997	1998	No.	%
VS only	185	261	195	104	50	97	109	114	1115	19.0
MSP only	71	82	39	34	43	34	24	57	384	6.8
SVF only	29	27	45	83	97	34	53	77	445	7.8
MSP & SVF	29	31	197	222	240	189	190	142	1240	21.8
VS & SVF	5	22	30	20	19	29	38	51	214	3.8
VS & MSP	293	225	54	17	23	29	21	41	703	12.4
VS, MSP, SVF	72	97	192	190	179	260	307	282	1579	27.8
Total	684	745	752	670	651	672	742	764	5680	100

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bia. There is usually a delay before these registrations occur and thus, for births, there will always be incomplete data, particularly for the most recent year because there has been less time for reporting. For mortality data, the individual may be in all three databases but under variations of their name which prevented a match. Over time, the proportion of events identified by the three sources has increased each year, while the events identified by only one source have decreased.

At the same time as the birth and death statistics project was underway, the Vital Statistics Agency had been working on a system to accurately compile population estimates for the Status Indian population of British Columbia. These population estimates are based on the Status Indian Entitlement File maintained by the Medical Services Plan of British Columbia which contains the name, gender, date of birth and mailing address of each Status Indian person registered with the Plan. The MSP file was adjusted for births and deaths by cross matching with historical annual files from the British Columbia Vital Statistics Agency.

Population estimation is a complex undertaking. Using the MSP file as the basis for deriving population estimates has both strengths and weaknesses. On one hand, the addresses in the MSP file enable the project to produce regional population estimates not available elsewhere. On the other hand, since declaration of Indian Status is voluntary, the file might not include Status Indian persons who are registered with the Medical Services Plan but whose premiums are already paid by a spouse, an employer or a social assistance program. Overall, the MSP file was considered to be the best available source for estimating the Status Indian population living in British Columbia. The British Columbia Vital Statistics Agency is working with First Nations and Inuit Health Branch to further develop the population estimate methodology.

All three databases (VS, SVF and MSP) include address information, so we can produce statistics for selected regions of the province. But at present we cannot distinguish between persons living on Indian Reserves and those residing off-reserve.

DISCUSSION

Using this methodology it is now possible to produce cred-

ible and detailed birth and death statistics for the Status Indian population of British Columbia. It is not possible in this paper to report on these statistics but these annual reports are available in hard copy [1] and will soon be on the World-Wide Web.

From the above information, it is apparent that unless an attempt is made to capture complete data, gross under reporting is possible. For example, before this system was utilized, the number of deaths reported among Status Indian people in any one year was about half the present number. Unless similar data capturing systems are utilized in other jurisdictions, it is best not to attempt to compare rates in one province with those in another or to roll up data on a national basis.

Work is presently being undertaken with the National Vital Statistics Registrars Association to improve the reporting of births and deaths for the Status Indian population across Canada. This will take some time to implement but will ensure a credible provincial and national reporting system.

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HUMAN T-LYMPHOTROPIC VIRUS TYPE I AND II INFECTIONS IN FIRST NATIONS ALCOHOL AND DRUG TREATMENT CENTRES IN BRITISH COLUMBIA, CANADA, 1992-2000

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ABSTRACT

Since 1992, prevalence data on HTLV-I and II have been collected as part of an ongoing viral seroprevalence study in clients of six First Nations alcohol and drug treatment centres in British Columbia, Canada. Prior studies indicate that the lifetime risk of clinical disease (neurologic or hematologic) resulting from HTLV-I infection is low (less than 5%) and HTLV-II to date has not been clearly associated with clinical disease. In 1993, the first cases of HTLV-I-associated myelopathy or tropical spastic paraparesis (HAM/TSP) were reported in four Aboriginal residents of British Columbia; these were the first reports of HTLV-I linked disease among Aboriginal persons in Canada. All clients of the treatment centres involved in this study were offered confidential, voluntary testing following pre-test counseling, and the results are given to participants before the residential session is complete. 1953 men and women were tested; 11 were positive for HTLV-1 (0.56%) and 33 were positive for HTLV-2 (1.8%). (*Int J Circumpolar Health* 2002; 61; 2: 98-103)

Keywords: HTLV-1, HTLV-2, First Nations, Aboriginal, North American Indian, HAM/TSP, Canada, British Columbia

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This study was designed to track the prevalence of HTLV infection in First Nations people entering several residential alcohol and drug treatment centres in British Columbia.

Human T-cell lymphotropic virus (HTLV) is a retrovirus, similar to HIV, but which replicates at a much slower rate. The virus is spread through breastfeeding, by sexual transmission (mainly male-to-female), and parenterally, by blood product transfusion and injection drug use. HTLV-I and II are endemic in various populations around the world; they also are found in intravenous drug users (IDUs). Coastal communities generally have a higher prevalence of HTLV-I. Both viruses are present in the indigenous peoples of South,

Central, and North America, including in BC First Nations (7,8). Phylogenetic studies have been unable to conclusively determine the source of the viruses in Amerindians, but the best available evidence suggests that they were present in at least one wave of the original colonization of the Americas 15,000 to 40,000 years ago.

HTLV-I infection is prevalent in central Africa and southern Japan; there are also clusters in isolated populations in northern Iran, the Philippines, Papua New Guinea, northern Australia and in other scattered pockets of indigenous peoples throughout the world (1,12). Several strains of the virus are known to be present in coastal First Nations people in British Columbia (8); they show similarities to strains from Japan (8) and Iran (13). Infection carries a 2-4% lifetime risk of HTLV-I associated myelopathy/tropical spastic paresis (HAM/TSP), a progressive, multiple-sclerosis-like spinal degenerative disease, and approximately the same risk of adult T cell leukemia/lymphoma; it may also cause arthropathy and uveitis (5). The first case reports of HAM/TSP amongst Canadian Aboriginals were published by Oger et al. in 1993 (6), involving four British Columbian First Nations people. This underscores the importance of tracking the seroprevalence of this virus.

HTLV-II is endemic in many Indian tribes in North and South America (10). It is also the predominant strain encountered in the intravenous drug user population in the United States (11). It has yet to be conclusively proven that HTLV-II causes any illness in those infected. Preliminary epidemiologic data suggests it may be associated with an increased relative risk of various infections, including abscesses, pyelonephritis, pneumonia, and possibly tuberculosis (3,4). Several cases of neurologic disease, similar to HAM/TSP, in the setting of HTLV-II infection have been reported. Reports of a link between HTLV-II and lymphoproliferative disorders have not been supported by epidemiologic evidence.

METHODS

The testing program, which began in January 1992, consists of an information workshop on sexually transmitted diseases and voluntary testing for HIV, viral hepatitis, HTLV-I and HTLV-2 (the results for HIV and Hepatitis B testing are reported separately). Part-time nurses are hired and trained

to coordinate the program.

All clients are offered the education workshop within two weeks of entering the centres. Clients are given the opportunity to participate in the testing program; those participating are given pre-test counseling by the nurse, and post-test counseling is carried out if at all possible prior to discharge from the centre.

Blood is submitted to the Provincial Laboratory at the British Columbia Centre for Disease Control Society in Vancouver, where testing by ELISA, with confirmation and viral typing by Western Blot, is performed. The provincial laboratory can usually determine the HTLV type present in positive tests, although occasionally the result is indeterminate; these results are excluded from the final analysis. The rate of positive tests were treated as negative results. The staff at the provincial laboratory and the researchers at the University of British Columbia provide, receive, and enter the test results in such a way that individuals cannot be identified except by the study nurses, in order to preserve confidentiality. The data are collected and reported by one of the investigators (RGM) at the Department of Health Care and Epidemiology, Faculty of Medicine, University of British Columbia.

RESULTS

A total of 1,953 men and women were tested.

In males the rate of HTLV-I infection is 3.1/1000 (95% CI 0.0-6.5/1000). For females the rate is 8.3/1000 (95% CI 2.6-14.0/1000). The overall rate is 5.6/1000 (95% CI 2.3-9.0/1000). When looked at by region, 8 of 10 positives were from Vancouver Island (Nanaimo or Campbell River regions).

For HTLV-II, the rate in males is 15.3/1000 (95% CI 7.6-23.0/1000), and in females 20.8/1000 (95% CI 11.8-29.8/1000). The overall rate is 17.9/1000 (95% CI 12.0-23.8/1000).

The rate rates of positive tests for HTLV-I and HTLV-II have not changed over the years (Table I).

DISCUSSION

For HTLV-I, the infection rates in this population are similar to rates of HIV (3.7/1000) and to chronic hepatitis B infec-

Table 1. Gender, HTLV results and ages.

	Negative	HTLV-I positive	HTLV-2 positive	Not tested	Total
Male	963	3	15	242	1223
Female	934	8	20	219	1182
Not specified	9	0	0	24	33
Total	1907*	11	35	485	2438
Average age	33	35.1	40.9	33.9	33.4
Male rate positive (per 1000)		3.1	15.3		
Female rate positive (per 1000)		8.3	20.8		
Overall rate		5.6	17.9		

*Includes 13 who tested positive but HTLV type could not be determined, and 4 whose results were equivocal (treated as negative in analyses). Also includes one person of unspecified gender.

tion (3.0/1000) (2). The seroprevalence rate of HTLV-I infection in clients entering First Nations alcohol and drug treatment centres (5.6/1000) is higher than that among volunteer blood donors in the United States (0.9/1000) (5), but lower than in some endemic areas, where seroprevalence rates are as high as 15% (8). The relatively high HTLV-I rate found on Vancouver Island is consistent with studies done by Oger and Werker, who found higher HTLV-I prevalence in coastal communities in BC (6). The overall HTLV-II rate of 17.9/1000 is similar to the prevalence of 16/1000 reported in samples drawn in the 1980s from the Nuu-Chah-Nulth of Vancouver Island (7), and higher than the rate in US blood donors of 2.2/1000 (5).

Rates of HTLV-II infection were three times higher than HTLV-I. The predominance of HTLV-II infection in this study, while typical of many more southern Native Americans, contrasts with the predominance of HTLV-I recently found in the Nuu-Chah-Nulth (7); this may reflect parenteral transmission of HTLV-II through intravenous drug use in our study population. The rates of positive tests for HTLV-I and HTLV-II have not varied much by year (Table II).

There is no treatment currently available or recommended for either HTLV-I or HTLV-II infected individuals. Those that test positive are notified of their status and told to inform their family physician. These individuals are advised to take precautions (condom use, avoid breast feeding and sharing of needles) to prevent virus transmission. Their contacts are not tested and it is not known whether they abide

Table II. HTLV-I and II test results by year.

Year	1992	1993	1994	1995	1996	1997	1998	1999	2000	All years
Anti-HTLV negative*	128	169	156	322	257	196	245	240	194	1907
HTLV-I positive	1	0	0	1	5	0	3	1	0	11
HTLV-II positive	3	8	3	3	3	3	5	5	2	35
Not tested	60	27	235	44	58	11	19	20	11	485
Total	192	204	394	370	323	210	272	266	207	2438
HTLV-I rate**	0.8	0	0	0.3	1.9	0	1.2	0.4	0	0.56
HTLV-II rate**	2.3	4.5	1.9	0.9	1.1	1.5	2.0	2.0	1.0	1.79

*includes those who tested positive but whose HTLV type could not be determined, and those whose results were equivocal (treated as negative in analyses).

**Prevalence of seropositivity per 100 people tested.

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by the advised precautions. Health practitioners in British Columbia, including physicians and community health nurses, were provided HTLV information in a comprehensive media campaign conducted in 1994.

At present there is no central registry and no way to effectively track those who test positive for HTLV. It is the authors' opinion that there is a need for an enhanced surveillance system to better track these individuals. This would permit them to be informed if there is a change in the availability of treatment, and could also be used for tracing if treatment options improve. In addition, these individuals could be followed to detect early disease in the HTLV-I infected and to determine whether the HTLV-II infected persons are at increased risk for any adverse health outcome.

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