

Underreporting of AIDS cases in Canada: a record linkage study

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To estimate the rate of underreporting of AIDS (acquired immune deficiency syndrome) to the Federal Centre for AIDS (FCA), in 1988 the initials, date of birth and place of residence of 66 patients with AIDS known to the Toronto Sexual Contact Study (TSCS), 65 patients with AIDS known to the Vancouver Lymphadenopathy-AIDS Study (VLAS) and other participants in both studies who did not have AIDS were sent to the Bureau of Epidemiology and Surveillance, FCA. The FCA conducted a manual record linkage to link these data to the national registry of reported cases. The rate of underreporting was 12% (8/65) for the VLAS and 18% (12/66) for the TSCS. The specific diagnosis was not related to the rate of underreporting. For the TSCS the rate of underreporting had increased from 0% in 1983-84 to 44% in 1987-88 ($p = 0.001$). Differences in the observed rates of underreporting between the two studies are likely the result of differences in the reporting responsibilities of physicians involved in the studies.

Afin de pouvoir évaluer la proportion de cas de SIDA (syndrome d'immunodéficience acquise) non signalés au Centre fédéral sur le SIDA (CFS) en 1988, les initiales, date de naissance et lieu de résidence de 66 patients atteints du SIDA et connus du Toronto Sexual Contact Study (TSCS), de 65 autres patients également atteints du SIDA et connus du Vancouver Lymphadenopathy-AIDS Study (VLAS) ainsi que d'autres personnes non atteintes du SIDA ont été référés au Bureau d'épidémiologie et de surveillance du CFS. Le CFS a effectué manuellement la corrélation entre ces données et celles contenues dans le registre national des cas rapportés. La proportion de cas non rapportés s'établit à 12% (soit 8 personnes sur 65) au VLAS et à 18% (soit 12 personnes sur 66) au TSCS. Le diagnostic spécifique n'avait aucun lien avec la proportion de cas non rapportés. Dans le cas du TSCS cette dernière est passée de 0% en 1983-84 à 44% en 1987-88 ($p = 0,001$). Les différences observées entre les deux bureaux quant aux cas étudiés relèvent vraisemblablement des différences existant entre les responsabilités des médecins travaillant dans ces bureaux en matière de signalement des cas.

Notifications of cases of AIDS (acquired immune deficiency syndrome) to public health authorities form the basis for monitoring the AIDS epidemic. These data are crucial in the allocation of resources for the provision of medical care, access to drugs and other services required by

patients with the syndrome. They are important for the provision of public health services and the planning of prevention programs. Indirectly they also serve as indicators of the size and trends of the HIV (human immunodeficiency virus) epidemic.

However, it is clear that the surveillance data

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have their limitations. The failure of physicians to report all diagnosed cases of AIDS results in underestimates of the number of cases. Underreporting leads to incorrect projections and modelling of the epidemic,^{1,2} which in turn may result in provision of insufficient resources to deal with the problem. Delays in the reporting cases may affect the interpretation of growth rates and changes.

If the scope of these limitations is identified and understood, adjustments can be made so that the surveillance data reflect reality more closely.³ Decisions about the allocation of resources can then be made on the basis of true need rather than underestimates. More important, those involved in reporting of cases can be made to see the extent of the problem and the importance of prompt reporting of all eligible cases.

We carried out a study to assess the level of underreporting of AIDS in Canada and to determine whether rates of underreporting have remained stable over time.

Methods

AIDS is a reportable disease in all the provinces, the Yukon Territory and the Northwest Territories. The date on which it became reportable varies from province to province and ranges from 1983 to 1988. AIDS became reportable in January 1983 in British Columbia and in March 1984 in Ontario. Physicians submit confidential case reports, including demographic, clinical and risk factor information, to their local health department. The information is provided to the provincial ministry of health and subsequently to the national surveillance program, the Bureau of Epidemiology and Surveillance, Federal Centre for AIDS (FCA). A standard reporting form developed by the Department of National Health and Welfare in collaboration with the National Advisory Committee on AIDS is used across the country. Quebec uses a provincial form that includes the same information as the national form. No active case finding is undertaken by public health authorities in any province or territory.

Two Canadian studies, the Toronto Sexual Contact Study (TSCS)⁴ and the Vancouver Lymphadenopathy-AIDS Study (VLAS),⁵ collect and maintain information on cases of AIDS in their respective cohorts. Both studies independently sent to the FCA the initials, date of birth and city of residence of the patients known to have AIDS and of other study participants who did not have AIDS. The FCA was not informed of the clinical status of people on the list. This information was used to conduct a manual record linkage with data in the national registry. For each linked case the FCA provided the initials, date of birth, place of residence, diagnosis, date of diagnosis and, when appli-

cable, date of death. The FCA performed the linkage in the first week of May 1988 for the VLAS data and the first week of November 1988 for the TSCS data.

The VLAS sent information on 961 past and present study participants: 65 were seropositive and had AIDS, 441 were seropositive but did not have AIDS when last seen and 382 were seronegative; for 73 the serologic status was unknown. The TSCS sent information on 210 people, of whom some were cohort members and some were index cases used to recruit the cohort members. Of the 66 patients known to have AIDS 25 were cohort members and 41 were index cases. Of the 144 other subjects 29 were cohort members who were seropositive but did not have AIDS and 115 were index cases whose last known diagnosis was persistent generalized lymphadenopathy (group III in the US Centers for Disease Control classification of HIV infection⁶).

The information for the 29 seropositive cohort members without AIDS in the TSCS and the 382 seronegative subjects in the VLAS was included to evaluate the specificity of the record linkage.

To reduce the likelihood that unlinked cases were a result of a delay in reporting, all AIDS cases diagnosed in the 3 months before the date on which the linkage was done were excluded from the analysis. This period is consistent with the median time lag in reporting (based on 3020 reported cases) identified by the FCA. The cutoff dates were Feb. 1, 1988, and Aug. 1, 1988, for the VLAS and the TSCS respectively.

The proportion of cases not reported was calculated by subtracting the number of linked cases from the number of known AIDS cases and dividing the difference by the number of known AIDS cases. Whenever cell size allowed, the Pearson chi-squared test was done to assess level of association. A Mantel-Haenszel chi-squared test, which assesses the linear association between the row variable and the column variable, was used to determine whether the year of diagnosis was associated with underreporting of cases.⁷

Results

The proportion of AIDS cases not reported was 12% (8/65) for the VLAS and 18% (12/66) for the TSCS ($\chi^2 = 0.48$, 1 degree of freedom, $p = 0.489$). The rate for both studies combined was 15%.

No linkages were made for the 382 seronegative subjects in the VLAS or the 29 seropositive subjects who did not have AIDS in the TSCS. Thus, the specificity of the national registry appears excellent for linkage based on the identifiers that we used.

The FCA identified three AIDS cases that the VLAS had not identified at the time the list was sent to the FCA. In two cases the syndrome was diagnosed after the list had been compiled and sent to

the FCA but before the FCA performed the linkage. The third case had been reported to the FCA but not to the VLAS project office. All three cases were confirmed by the patients' physicians. The FCA also identified six subjects with AIDS in the TSCS who when last seen were not known to have AIDS; all six were index cases whose last known diagnosis was persistent generalized lymphadenopathy. We were unable to confirm the FCA's AIDS identification because the index cases were not followed prospectively. On the basis of the VLAS data no false linkages were made.

The specific diagnosis was not related to the proportion of cases not reported (Table 1).

For the VLAS the proportion of cases not reported remained stable over the years, whereas for the TSCS the proportion increased from 0% in 1983-84 to 44% in 1987-88 ($p = 0.001$) (Table 2).

Discussion

The rates of underreporting of AIDS observed in our study are similar to those observed in other countries with other sources of data. A review of death certificates in four US cities indicated underreporting rates of 0% to 17%.⁸ In a study of changes in death rates in England and Wales the rate of underreporting was estimated to be around 20%.² The overall rate for Switzerland, based on matching death certificates with surveillance registry data, was estimated at 24.8%.⁹ Johnson, Montano and Wallace,¹⁰ who also used death certificates to estimate

the completeness of AIDS case reporting, recently reported a rate of 24.9% for Ontario. To our knowledge our study is the first attempt to assess completeness of a surveillance registry by means of documented AIDS cases from a cohort study rather than death certificates.

The existence of underreporting is no surprise. It is reassuring that the rates of underreporting are not as high as they are for other communicable diseases.⁸ Knowing these rates allows correction factors to be incorporated into models projecting the incidence, prevalence and costs of AIDS. If one assumes the minimum rate to be that observed for the VLAS (12%) and the maximum rate to be that observed for the TSCS (18%), between 218 and 323 more AIDS cases should have been reported to the FCA by the time the linkage was done.

The differences in the rate of underreporting between the two studies are likely the result of differences in their reporting responsibilities. In the TSCS the project physician refers any patient suspected to have AIDS to treating physicians, who are then responsible for confirming the diagnosis, reporting the case to the public health authorities and beginning appropriate therapy. The nature and date of diagnosis recorded by the project physician are based on the report of the treating physician. In contrast, the physicians involved in the VLAS are also the treating physicians and hence bear the primary responsibility for reporting cases.

When assessing underreporting it is necessary to take into account reporting delays. The FCA found that the median time between the date of diagnosis and the date of reporting was 3 months. Reporting delays do not appear to explain the increasing rate of underreporting over time for the TSCS. The most recently diagnosed AIDS case reported to the FCA had been diagnosed in January 1988, 10 months before the linkage was done. The other cases not linked had been diagnosed before September 1987, 14 months before the linkage. Johnson and col-

Table 1: Relation between specific diagnosis and linkage of cases of AIDS (acquired immune deficiency syndrome) with the Federal Centre for AIDS (FCA) registry

Study; diagnosis	No. (and %) of cases not reported
Toronto Sexual Contact Study (TSCS) ^a (n = 66)	
<i>Pneumocystis carinii</i> pneumonia (n = 35)	5 (14)
Kaposi's sarcoma (n = 23)	5 (22)
Other* (n = 2)	1 (50)
AIDS, specific diagnosis unrecorded (n = 6)	1 (17)
Vancouver Lymphadenopathy-AIDS Study (VLAS) ^b (n = 65)	
<i>P. carinii</i> pneumonia (n = 27)	3 (11)
Kaposi's sarcoma (n = 22)	2 (9)
Other† (n = 16)	3 (19)
Both (n = 131)	
<i>P. carinii</i> pneumonia (n = 62)	8 (13)
Kaposi's sarcoma (n = 45)	7 (16)
Other (n = 18)	4 (22)
AIDS, specific diagnosis unrecorded (n = 6)	1 (17)

*Wasting, constitutional/neurologic disease.

†Immunoblastic lymphoma, lymphoma of the brain, candidiasis (bronchial) and *Mycobacterium avium* or *M. kansasii* infection.

Table 2: Relation between the year of diagnosis of AIDS* and linkage with the FCA AIDS registry

Study; year of diagnosis	No. (and %) of cases not reported
TSCS†	
1983-84 (n = 18)	0 (0)
1985-86 (n = 31)	4 (13)
1987-88 (n = 16)	7 (44)
VLAS‡	
1983-84 (n = 10)	0 (0)
1985-86 (n = 32)	4 (12)
1987-88 (n = 23)	4 (17)

*Missing for one case.

†Mantel-Haenszel χ^2 for trend = 11.1, 1 degree of freedom (df), p value for trend = 0.001.

‡Mantel-Haenszel χ^2 for trend = 1.73, 1 df, p value for trend = 0.189.

leagues¹⁰ also found a significant increase in underreporting of deaths due to AIDS between 1985 and 1986. The US National Academy of Sciences predicted in its 1986 report that underreporting would likely increase as awareness of the main modes of acquiring AIDS increased and the novelty of the syndrome decreased.³

The fact that rates of underreporting may be increasing is of great concern. If the rates are increasing, the decrease in the numbers of cases reported may be misinterpreted as a reduction in the growth of the epidemic. A perceived reduction may mean reduced government spending on AIDS and reduction in the general public's concern about the spread of the disease.

Physicians must be encouraged to report cases of AIDS. They must be made to understand that underreporting of cases could result in underallocation of resources required to meet the needs of current patients with AIDS and the long-term requirements.

It is imperative that further studies be conducted to determine whether the rates of underreporting identified by the VLAS and the TSCS are applicable to other health care settings in other provinces in Canada.

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References

1. Wells GA, Tostowaryk W, Rylett DJ: Current and future trends of AIDS in Canada. In *AIDS: a Perspective for Canadians. Background Papers*, Royal Society of Canada, Ottawa, 1988: 81-110
2. *Short-term Prediction of HIV Infection and AIDS in England and Wales: Report of a Working Group*, Dept of Health, Welsh Office, HMSO, London, 1988: 1-88
3. National Academy of Sciences: *Confronting AIDS: Directions for Public Health, Health Care, and Research*, Natl Acad Pr, Washington, 1986: 86-89
4. Coates RA, Soskolne CL, Read SE et al: A prospective study of male sexual contacts of men with AIDS-related conditions (ARC) or AIDS: HTLV-III antibody, clinical, and immune function status at induction. *Can J Public Health* 1986; 77: 26-32
5. Schechter MT, Boyko WJ, Douglas B et al: The Vancouver Lymphadenopathy-AIDS Study: 6. HIV seroconversion in a cohort of homosexual men. *Can Med Assoc J* 1986; 135: 1355-1360
6. Revision of the CDC surveillance case definition for acquired immunodeficiency syndrome. *MMWR* 1987; 36: 1S-15S
7. SAS Institute Inc: *SAS User's Guide: Statistics*, Version 5 Edition, Cary, NC, 1985: 412-413
8. Hardy AM, Starcher ET, Meade Morgan W et al: Review of death certificates to assess completeness of AIDS case reporting. *Public Health Rep* 1987; 102: 386-391
9. Engel R, Minder C, Spuhler T et al: Evaluation of AIDS surveillance in Switzerland: estimation of underreporting and impact of active surveillance [abstr]. Presented at the Vth International Conference on AIDS, Montreal, June 4-9, 1989
10. Johnson RJ, Montano BL, Wallace EM: Using death certificates to estimate the completeness of AIDS case reporting in Ontario in 1985-87. *Can Med Assoc J* 1989; 141: 537-540

Conferences

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June 25-29, 1990: Canadian Public Health Association 81st Annual Conference (hosted by the Ontario Public Health Association)

Harbour Castle Westin, Toronto

Canadian Public Health Association, 400-1565 Carling Ave., Ottawa, Ont. K1Z 8R1, (613) 725-3769, FAX (613) 725-9826; or Ontario Public Health Association, 202-468 Queen St. E, Toronto, Ont. M5A 1T7, (416) 367-3313, FAX (416) 367-2844

July 18-21, 1990: Genetics Society of America 59th Annual Meeting (cohosted by the Genetics Society of Canada)

San Francisco Hilton

Administrative Office, Genetics Society of America, 9650 Rockville Pike, Bethesda, MD 20814; (301) 571-1825

Sept. 14-17, 1990: 67th Annual Meeting of the Canadian Paediatric Society (held in conjunction with the Annual Meeting of the Royal College of Physicians and Surgeons of Canada)

Metro Toronto Convention Centre

Dr. Victor Marchessault, executive vice-president, Canadian Paediatric Society, 401 Smyth Rd., Ottawa, Ont. K1H 8L1; (613) 737-2728

Sept. 15-23, 1990: British Medical Association Annual Scientific Meeting

Edinburgh

Marie Claire Bédard, CMA Travel Centre, Meetings Department, P.O. Box 8650, Ottawa, Ont. K1G 0G8; 1-800-267-6356; FAX (613) 731-9013

Sept. 22-28, 1990: 23rd International Congress on Occupational Health: Sharing Solutions

Montreal Convention Centre

Secretariat, 23rd International Congress on Occupational Health, 2-58 de Brésolas St., Montreal, PQ H2Y 1V5; (514) 499-9835, FAX (514) 288-4627

Le 30 sept-le 3 oct 1990: 4e Congrès international francophone de gérontologie

Palais des congrès, Montréal

Les services de congrès GEMS, 100-4260 Girouard, Montréal, PQ H4A 3C9; (514) 485-0855, FAX (514) 487-6725