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Undiagnosed HIV Infections in Canada

At a Glance

- At the end of 2008, an estimated 65,000 people were living with HIV (including AIDS) in Canada.
- Of these, approximately 16,900, or 26%, were not aware of their infection.
- Given the new treatments available for HIV, it is more important than ever that all Canadians should be able to access HIV testing.

Introduction

This Epi Update presents information on the estimated number of Canadians who were HIV infected but unaware of their infection at the end of 2008. It also summarizes available data on the characteristics of people tested for HIV in Canada.

HIV Infected But Unaware in Canada

It is important to note that data on positive HIV tests represent only those who have tested positive for HIV infection and do not represent everyone who has been infected with HIV, as some who have been infected have not yet accessed testing. The Centre for Communicable Diseases and Infection Control (CCDIC) recently published estimates of HIV prevalence in Canada to the end of 2008 (for details, please see Chapter 1 of this Epi Update series, entitled "National HIV Prevalence and Incidence Estimates in Canada for 2008").

It was estimated that approximately 65,000 (54,000-76,000) Canadians were living with HIV infection (including those living with AIDS) at the end of 2008. This number includes those who were aware of their infection (had had a positive HIV test) and those who were unaware of their infection (had not been tested for HIV yet or had not known their testing result). There have been 67,442 positive HIV tests reported to CCDIC since testing began in November 1985 to December 31, 2008, which translates to about 70,400 after adjusting for underreporting and duplicates. Of these, we further estimated that approximately 22,300 have died. Thus, there were an estimated 48,100 (70,400 minus 22,300) Canadians living with HIV infection in 2008 who had been given a diagnosis of HIV (tested positive) and were therefore aware of their HIV status. Since an estimated total of 65,000 people were living with HIV in Canada in 2008, the remaining 16,900 (range of 12,800-21,000), or 26% of prevalent cases, were unaware of their HIV infection. This figure is slightly less than the estimate of 27% who were unaware of their HIV status in 2005.

The estimated percentage of people living with HIV who are unaware of their HIV status varies by exposure category. Approximately 19% of infected people in the MSM (men who have had sex with men) exposure category and 25% of those in the IDU (people who inject drugs) exposure category are unaware of their HIV infection. By comparison, there is a much higher proportion of individuals (35%) who are unaware in the combined heterosexual exposure category (Figure 1). These percentages correspond to an estimated 6,000 (4,500-7,500) MSM, 2,800 (2,000-3,600) IDU and 7,000 (5,200-8,800) people in the combined heterosexual exposure category who were unaware of their HIV-positive status at the end of 2008.



40% 35% 25% 25% 10% 10% 5% 0% MSM IDU Heterosexuals Overall

Exposure category

Figure 1. Estimated proportion of people with undiagnosed HIV infection by exposure category in Canada, 2008

A more direct measure of the proportion of people in certain subpopulations who are HIV infected but unaware of their infection is available through the national, secondgeneration HIV surveillance systems. This is possible by comparison of self-reported HIV status (by questionnaire) with HIV serostatus, measured by the biological specimen obtained from participants. Using this methodology, the "unaware" individuals were survey participants who reported that they had never been tested for HIV or that their HIV status was negative or unknown, whereas HIV testing performed on their biological specimens indicated that they were HIV positive. In the I-Track, the surveillance system focused on people who inject drugs, the overall proportion of participants with HIV-positive specimens who were unaware of their positive status was 22.3% in Phase 1 (sentinel site range: 11.1% to 50.0%, surveys conducted in 2003-2005) and 21.0% in Phase 2 (sentinel site range: 0.0% to 43.5%, surveys conducted in 2005 to 2008). In the M-Track, the surveillance system focused on gay, bisexual and other MSM, the overall proportion of HIV infected participants who were unaware of their HIV positive status was 19.1% (sentinel site range: 12.5% to 23.2%).

For more details on the "Track" second-generation HIV surveillance systems, see Chapter 3 of these *Epi Updates*, "HIV Testing and Surveillance Systems". Chapter 9, "HIV/AIDS among Gay, Bisexual and other Men who have sex with Men (MSM) in Canada", provides more information on the epidemiology of HIV and AIDS among MSM, and Chapter 10, "HIV/AIDS among People Who Inject Drugs in Canada", provides information on HIV infection among IDU.

Comparisons of Proportion Undiagnosed in Other Developed Countries

Despite the widespread availability of antiretroviral treatment and extensive promotion of HIV testing, an estimated 26% of HIV infections remained undiagnosed in Canada in 2008. The situation is very similar in other high-income countries. For example, the percentage of HIV-positive people without a diagnosis was estimated to be 21\% in the United States in 2006, 130% in the European Union in 2008² and 27% in the United Kingdom in 2008.³ We estimated that among MSM in Canada, 19% of people living with HIV were unaware of their HIV positive status, which is comparable with a recent report (20%) from Australia, 4 slightly lower than the rates estimated in the US $(23.5\%)^5$ and the UK $(26.9\%)^3$, and much lower than the rate from a survey in Scotland (41.7%). We estimated that among IDU in Canada, 25% of people living with HIV were unaware of their HIV status, which is very similar to recent estimates in the UK (25.5%)³ but higher than estimates in the US (14.5% of male IDUs and 13.7% of female IDUs).5 Our estimate of 35% in the heterosexual exposure category is slightly higher than the rate estimated in the UK (27.1%)³ and the US (26.7% of men and 21.1% of women).⁵

HIV Testing and Reporting in Canada

HIV testing first became available in Canada in 1985. Since then, individuals have had the opportunity to access HIV testing services through either nominal or nonnominal testing at a doctor's office or clinic, or through anonymous testing sites available in some provinces. At present, nominal/name-based and non-nominal/nonidentifying HIV testing methods are widely available in Canada; however, anonymous HIV testing is available in only seven provinces (for details, please see Chapter 3, entitled "HIV Testing and Surveillance Systems").

Characteristics of Persons Tested for HIV

There has been no new Canada-wide survey available regarding HIV testing behaviour since 2003. A Canadawide survey conducted in March 2003 of randomly selected individuals above 15 years of age revealed that just over one-quarter (27%, 29% of men and 24% of women) reported ever having been tested for HIV, excluding testing for the purposes of insurance, blood donation and participation in research.⁷ The figures from this 2003 survey show that a higher proportion of individuals reported having been tested than in a January 1997 Canada-wide survey, which found a corresponding figure of 18.6% of men and 16.2% of women aged 15 years and older (excluding tests for blood donation and insurance purposes).89 However, the proportion of people who had been tested in the previous 2 years did not increase (42% in 2003 and 57% in 1997). The results of a 1996 survey showed that, taking into account ancillary testing such as for blood donation or life insurance purposes, 41% of men and 31% of women in Canada had ever been tested for HIV.10

National surveys and studies of the general population suggest that those who report risk factors are more likely to be tested:

- Among heterosexuals, those with two or more partners in the previous year were more likely to be tested than those with one partner (50.5% versus 17.4%). The percentage of Canadians being tested was higher among individuals who reported casual partners (45%); this percentage increased with the number of partners, from 30% among those reporting one partner to 41% among those reporting two partners and 51% among those reporting three partners. Of individuals who reported having had a sexually transmitted infection (STI) in the previous 5 years, 58% had been tested compared with 17.4% of those who did not report an STI.89
- For men, the testing rate was higher among MSM (71%), IDU (62%), those who had received blood or clotting factor between 1978 and 1985 (27%) and those who had had a partner with a risk factor (IDU, received blood or clotting factor between 1978 and 1985 or came from a country endemic for HIV) (30%).^{8,9} For women, testing was higher among those who had received blood or clotting factor between 1978 and 1985 (32%) and those who had had a highrisk partner (38%).¹⁰

- Testing was highest among individuals aged 25 to 34 years. Even after all other risk factors had been taken into account, those aged 45 years and over were still less likely to be tested than those younger than 45 years.⁸⁻¹⁰ In the survey conducted in March 2003, Canadians aged 25-34 years and 35-44 years were more likely to have been tested (46% and 35% respectively).⁷
- Although national surveys have found that those reporting risk factors such as use of intravenous drugs, sex between men, or having multiple sex partners are more likely to be tested, a substantial proportion of individuals reporting risk factors have not been tested recently or have not been tested at all. For example, in a 1997 national survey, among those who reported having had more than one partner in the previous year and not having used condoms consistently, 53% of men and 38% of women had never been tested.^{7,8}
- Targeted studies have shown that a large proportion of individuals in higher-risk populations have been tested for HIV. The proportion who reported ever having been tested was 86.2% among M-Track participants in Phase 1 (2005-2007)¹¹ and 91.9% among I-Track participants in Phase 2 during 2005-2008.¹² An Ontario study of Black MSM between 2007 and 2008 showed that 144 men (85.7%) had previously been tested for HIV.¹³ These rates are much higher than the 63% of MSM respondents in a national study in 1991 who indicated that they had been tested for HIV¹⁴ and slightly higher than the 78% of MSM who responded in the Ontario Men's Survey in Ontario in 2002.¹⁵
- However, a national study involving Canadian Aboriginal youth found that 51% (210 of 413) had ever been tested for HIV;¹⁶ in a study of Quebecers of Haitian origin (2007-2008), 43.1% of the study participants reported ever having been tested for HIV;¹⁷ and the proportions that reported having been tested within the previous two years were 67.4% of M-Track participants in Phase 1 (among those who reported that their most recent HIV test result was negative)¹¹ and 63.9% of I-Track participants in Phase 2.¹²
- There are several factors that may relate to low uptake of HIV testing. In M-Track Phase 1 (2005-2007), young age, low personal income, never having injected drugs and no sex in the previous 6 months were related to lower odds of HIV testing. In I-Track Phase 2 (2005-2008), less frequent injecting, less use of needle exchange programs, Aboriginal ethnicity, young age and less education were all factors related to lower

rates of HIV testing.12

Comment

It has been estimated that approximately 16,900 people or 26% of the HIV-infected population were unaware that they were infected at the end of 2008. The size of the undiagnosed group is especially difficult to estimate because, without testing, those individuals are "hidden" to the health care and disease monitoring systems. It is important to reach this group since individuals whose infection has not been diagnosed are unable to take advantage of available treatment strategies or appropriate counselling to prevent the further spread of HIV. The transmission rate in the undiagnosed group is likely higher than that of the tested and diagnosed group.¹⁸ Studies have found that the frequency of high-risk sexual behaviour was reduced substantially after HIV diagnosis.¹⁹ To help stem the HIV/AIDS epidemic, it is important to increase the number and proportion of people living with HIV who receive testing and are informed of their serostatus.18

HIV testing is important not only for prevention and control measures but also for the benefit of the individuals who are tested. Knowledge of one's HIV status can be useful for several reasons. Counselling received at the time of HIV testing can provide critical information about how to reduce the risk of HIV infection if an individual is HIV negative. If an individual is found to be HIV infected, consideration can be given to starting antiretroviral therapy. In the case of pregnant women, treatment can

reduce the chances that the infant will be infected, from 35%-40% to 2% or less.²⁰

People at high risk of HIV (such as MSM or IDU) more frequently test for HIV, but scaled-up and targeted promotion of HIV testing is still needed in certain subpopulations that access testing less frequently (such as younger individuals and those with lower income and lower education levels). In order to better inform interventions, further information is needed about individuals who are at risk of HIV but have not been tested. Given the findings to date and the fact that new treatments are available for HIV infection, it is more important than ever that all Canadians, particu-

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larly those at highest risk of infection, should be able to access HIV testing.

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