What is the True Prevalence of HIV in New York City:
Estimating the number of undiagnosed and unreported persons living with HIV and AIDS, 2003

Lucia V. Torian, Yusuf Bembom, Thomas R. Frieden

The New York City Department of Health and Mental Hygiene, HIV Epidemiology Program, Office of the Commissioner of Health

Abstract

Background: New York State implemented reporting of HIV infection on June 1, 2000. Despite these efforts, the surveillance system does not capture persons living with HIV/AIDS who are not in care, or those whose infections were not diagnosed or reported. Undiagnosed persons are defined as those who have been infected with HIV for at least 12 months and have not been tested. The resulting prevalence estimate is an underestimate.

Methods: As of December 31, 2003, there were 68,675 known PLWHA in NYC. An unknown number of persons were (1) cases reported after June 1, 2000, who were not diagnosed or treated; (2) diagnosed prior to June 1, 2000, but had no reported event; (3) diagnosed prior to June 1, 2000, but died without a subsequent reportable event; (4) known cases diagnosed before June 1, 2000, not reported. To provide an estimate of the number of known cases present in NYC, we used surveillance data and a number of assumptions to estimate the number of cases reported.

Results: An estimated 11,338-45,914 PLWHA remain undiagnosed. Between 7,968 and 14,463 are not diagnosed. Estimates for unreported cases were broken down by risk and demographic characteristics. The prevalence of HIV in NYC is estimated to be 22-44% greater than that measured by the HIV surveillance system. This local exercise provides NYC with valuable data on the size and characteristics of its undiagnosed population, which can be used to plan testing and early detection campaigns as well as to project the need for future services.

Discussion

This analysis suggests that between 17,500 and 187,100 New Yorkers are living with HIV/AIDS (1.1 - 2.1% of the city’s population), and that there is a high burden of undiagnosed HIV in NYC (as much as 40%-60% of HIV cases). NYC’s surveillance system may not adequately capture persons who fall into these categories. (Continued)

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