



GENERAL TOPICS

25 Years of HIV in New York City: Lessons from Surveillance

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INTRODUCTION

HIV is now endemic in New York City, one of the original foci of the human immunodeficiency virus (HIV) epidemic. Acquired immunodeficiency syndrome (AIDS) case rates, which peaked in 1993, continue to decline. Mortality has been reduced by 70%, following the introduction of multiple antiretroviral medicines and improved prophylaxis for opportunistic infections.¹ The greatly improved survival rate has resulted in a steadily rising number of New Yorkers living with AIDS, despite declining numbers of new AIDS diagnoses. There has also been a shift in the characteristics of persons reported with AIDS, from a predominance of white men who report sex with men, to minorities with exposure to HIV through injecting drug use (IDU) and heterosexual transmission.² Success in HIV prevention is evidenced by declining HIV seroprevalence in many groups, disappearance of infections related to blood and blood products, and near elimination of mother-to-child transmission of HIV.^{3,4}

This report details what is known about the first 25 years of HIV in New York City, from public health surveillance, including AIDS surveillance, HIV-related mortality, and HIV serosurveys. Changes in the epidemic over time have led to changes in public health surveillance. The surveillance effort has been refocused to ensure ascertainment of new areas of epidemic spread and to facilitate the evaluation of prevention activities.

Although 2001 marks the 20th anniversary of the condition that came to be called AIDS, HIV probably entered New York City approximately 25 years ago. Evidence for this comes from a cluster of perinatally infected children born in 1977 to mothers who had histories of injecting drug use⁵ and retrospective searches for cases of apparent AIDS that occurred prior to the recognition of the syndrome, in 1981. There were 53 cases reported in New York City with AIDS-defining opportunistic illness diagnosed prior to 1981.

Additional information suggests that HIV was present before 1981 in New York City. There are anecdotes that in the late 1970s some men afflicted with Kaposi's sarcoma questioned the provenance of this cancer and noted that it seemed

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to be a problem among a small group of young and middle-aged gay men (K. Unger, oral communication, New York City, August 1981). Official recognition by the medical community was delayed until the spring of 1981 when physicians in New York City and California reported Kaposi's sarcoma and *Pneumocystis carinii* pneumonia in previously healthy young gay men.⁶

HIV, the virus that causes AIDS, was identified in 1983.⁷ An antibody detection test was developed in 1984, and the test was licensed for commercial use in 1985.⁸ Serosurvey data on selected populations and HIV reporting, required in New York State by a recent law,⁹ contribute insights into the extent and pattern of the epidemic in New York City. However, serosurveys have limited ability to describe HIV prevalence in the whole population, and HIV reporting counts those individuals who were tested for HIV and misses individuals who are not receiving medical care. Although the serologic test for the virus has been available for nearly 20 years, reported cases of AIDS and HIV mortality have been the most consistent measure of the pattern and volume of HIV in the community because both are visible events, diagnosed by medical providers, not dependent on whether a person sought medical attention and HIV testing. The case definition for AIDS has been expanded over time, most notably with the addition in 1993 of a CD4 T-lymphocyte count under 200 as an AIDS-defining condition. However, opportunistic illness has remained reportable, and persons with AIDS who are not in care and not reported with CD4 T lymphocytes less than 200 are still liable to progress and be reported with an opportunistic illness or with HIV-related death.

OVERVIEW OF TRENDS IN AIDS CASES AND HIV-RELATED MORTALITY

AIDS surveillance was implemented in New York City in cooperation with the Centers for Disease Control and Prevention (CDC) in 1981. In 1983, a New York State regulation required the reporting of persons meeting the CDC-defined AIDS case definition.¹⁰ Surveillance for AIDS has been an active, systematic process, with 85%–90% of all diagnosed cases reported.¹¹ Methods for AIDS surveillance data collection and management are detailed elsewhere.^{12,13}

New York City has a greater number of AIDS cases than any other city in the United States, with a cumulative total of 122,758 cases reported through 2000. This represents 17% of AIDS in the US, reported from a city with 3% of the nation's population.¹⁴ An estimated 140,000 New Yorkers are living with HIV (over 46,000 with AIDS) (New York City Department of Health, unpublished data, 1999). In 1999, HIV remained the leading cause of death in New Yorkers aged 25–44 years (and the third leading cause of death overall for black and Hispanic New Yorkers of all ages).¹⁵

Figure 1 shows the distribution of AIDS cases by year of diagnosis in adults and adolescent men and women and in children under 13 years old. Figure 2 shows the number of persons living with AIDS, HIV mortality, and death rates by calendar year. The number of deaths among persons with AIDS remained constant from 1991 to 1995. The declining death rate during this period is likely due to a shift in the timing of AIDS diagnoses to earlier in the course of infection (as CD4 > 200 was added as an AIDS-defining condition). However, the absolute number of AIDS deaths in New York City declined dramatically beginning in 1996, while the number of persons living with AIDS continued to rise. This decline in the number of

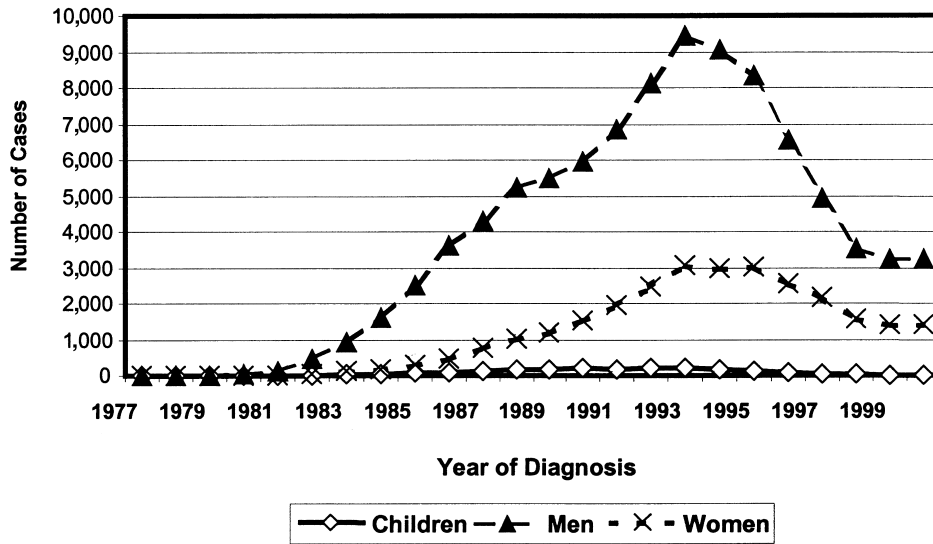


FIGURE 1. AIDS cases in men, women, and children under 13 in New York City by year of diagnosis, 1977–1999.

deaths and in death rates and the overall increase in survival is attributable to the widespread use of multiple antiretrovirals beginning in 1996.¹⁸

The New York City AIDS epidemic is mainly localized in neighborhoods already suffering from the economic and social marginalization that fuel the intersecting epidemics of drug use and sexually transmitted disease (STD).¹⁶ A major shift in geographic distribution of persons diagnosed with AIDS in New York City is attributable to the decline in the number of AIDS cases in men who have sex with men after 1985. Prior to 1985, over half of persons with AIDS lived in Manhattan.

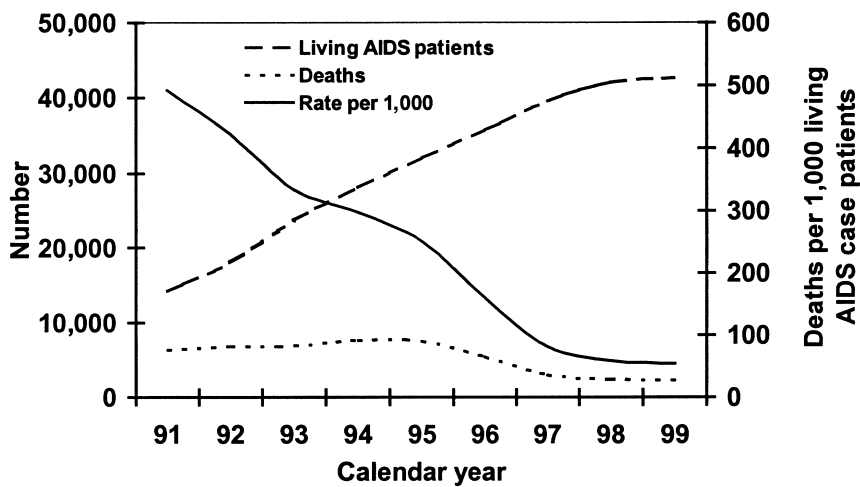


FIGURE 2. Persons living with AIDS, AIDS deaths, and death rate, New York City, 1991–1999.

Today, two thirds of these persons reside in boroughs other than Manhattan, including 24% in Brooklyn and 20% in the Bronx.¹⁷

CHANGES IN CHARACTERISTICS OF PERSONS DIAGNOSED WITH AIDS

Changes in Risk of Persons Diagnosed with AIDS

Although AIDS was first recognized in white men who have sex with men, it was soon realized that AIDS was also occurring in New York City's large population of injecting drug users and their sex partners, in children, and in people who had received blood or blood products. AIDS was diagnosed in men, women, and children, in persons of all socioeconomic strata and all racial and ethnic backgrounds.

Trends in proportions of cases in men and women by risk are shown in Figs. 3a and 3b. Early in the epidemic, men having sex with other men was the most common risk. During the late 1980s and the early 1990s, the New York City crack/cocaine epidemic fueled heterosexual transmission of HIV through increased unsafe sexual activity and exchange of sex for money and drugs.¹⁸

Sexual exposure to an HIV-infected person has always been the leading risk for HIV in New York City, as it is worldwide. The proportion of cases in men and women attributed to heterosexual exposure has been rising over the past decade.¹⁹

Changes in Race/Ethnicity

Except for early cases in white men who reported sex with men, HIV has been most prevalent in black and Hispanic New Yorkers. For a number of years, blacks and Hispanics have outnumbered whites even among cases in men who have sex with men. Figure 4 shows the increasing proportion of AIDS cases occurring in blacks and the concomitant decreasing proportion in whites. Less than 1 percent of reported cases of AIDS have been in Native Americans or Asians and Pacific Islanders.

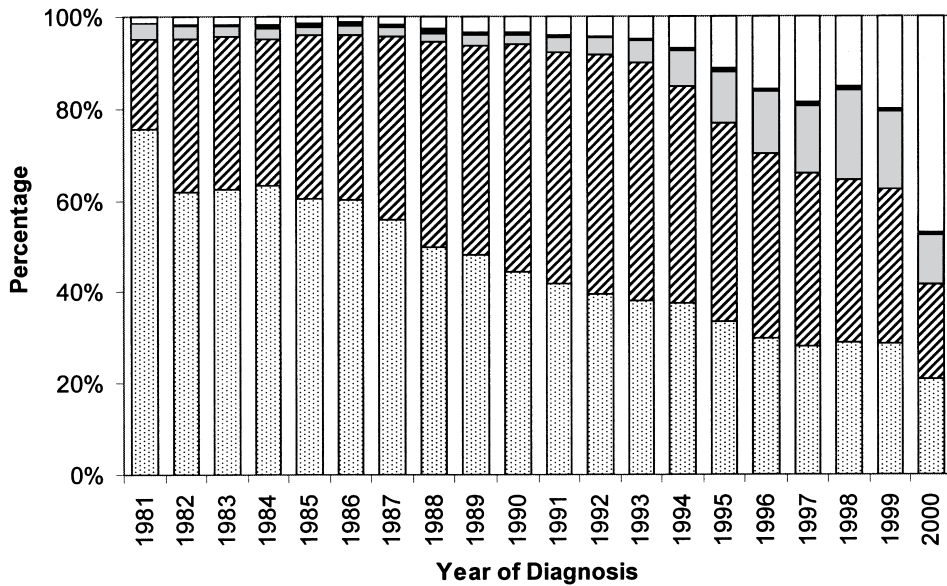
Changes in Age and Gender

Women constitute an increasing proportion of newly diagnosed cases of AIDS, representing 10% in 1981 and escalating to 30% in 2000. During the 1980s, a majority of women reported with AIDS were IDUs; in the past five years most of the women reported with AIDS were infected heterosexually.

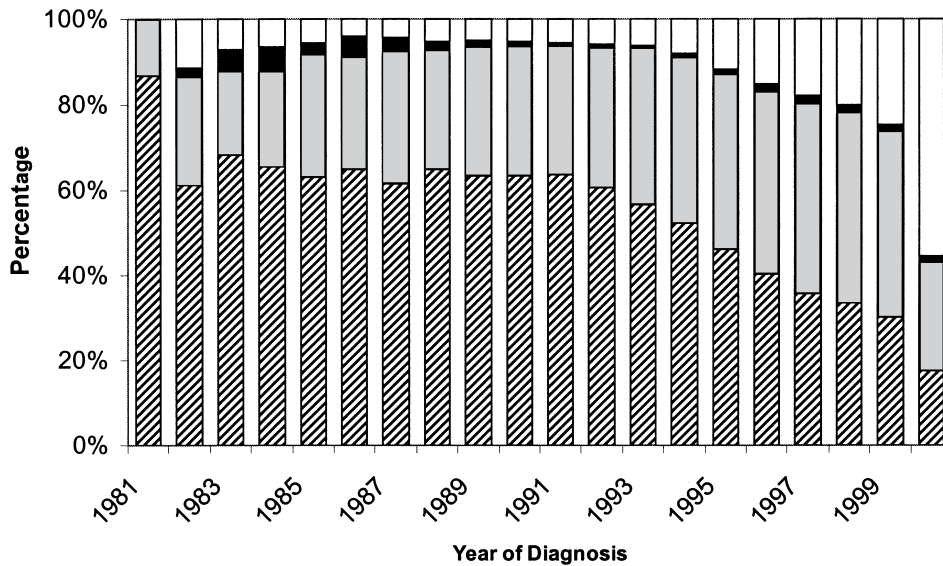
Median age at diagnosis of persons diagnosed with AIDS has risen steadily from 35 years old in 1982 to 41 years in 2000. Age at diagnosis for women has gone from 31 to 40 years and for men from 35 to 42 years.

Vanishing Cases in Children

Pediatric AIDS is defined as cases of AIDS diagnosed in those younger than 13 years. Over 96% of pediatric AIDS in New York City is due to mother-to-child transmission. The number of new AIDS diagnoses in children peaked at 203 in 1992 and has plummeted in the past 5 years: Only 26 cases were reported for 2000. This decline is due to falling numbers of HIV-infected women delivering babies in New York City,²⁰ the success of azidothymidine (AZT) and other antiretrovirals in decreasing the likelihood of mother-to-child transmission, and improved treatments for HIV-infected children, preventing the progression to AIDS.²¹



(a) MSM IDU HETERO Trans NIR



(b) IDU HETERO Trans NIR

FIGURE 3. Distribution of risk among (a) men and (b) women with AIDS, New York City, 1981–2000 (HETERO, heterosexual; IDU, injecting drug use; MSM, men who have sex with men; NIR, no risk identified; Trans, blood transfusion associated).

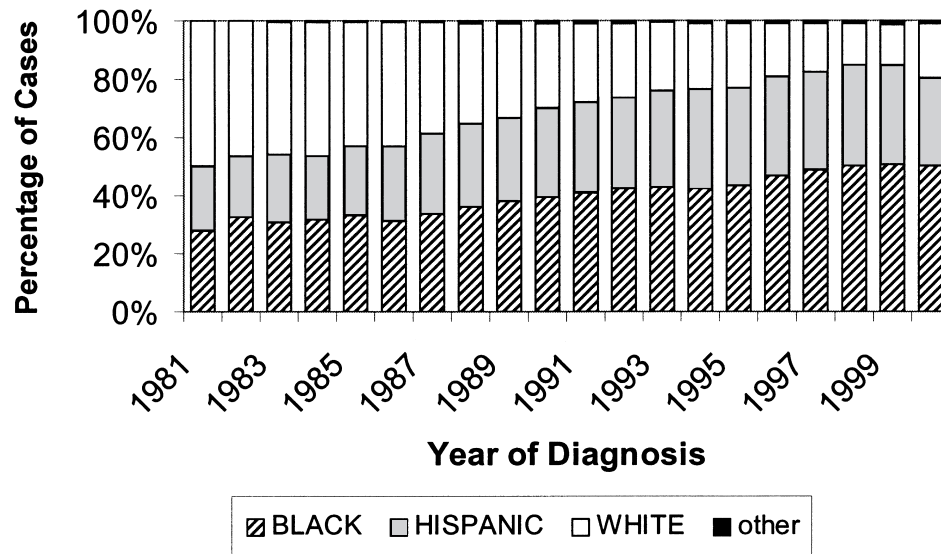


FIGURE 4. AIDS in adults and adolescents by race/ethnicity, by year of diagnosis, New York City Department of Health, 1981–2000.

HIV-Related Mortality

Deaths reported to New York City's independent vital registration system are used to monitor the number of HIV deaths. A dramatic decline in mortality began in 1996, when combination antiretroviral therapy that included protease inhibitors was introduced.²² After 3 years of steady decline, deaths due to HIV leveled off at about 2000 per year.²³

AIDS is highly visible, with similar patterns of opportunistic illness in all population groups. This has made AIDS relatively easy to monitor, with consistency in surveillance year to year. However, over the past decade, AIDS has become less valuable as a tool to monitor the HIV epidemic. The median incubation period from HIV to AIDS prior to the introduction of multiple antiretroviral therapy was about 10 years. Although quite long, this was not originally a prohibitive limitation as the incubation period was consistent across population and risk groups and over time. Now, incubation time to AIDS is lengthened and variable, depending on access to improved and targeted antibiotic prophylaxis to prevent some opportunistic illness and on multiple antiretroviral therapy with protease inhibitors since 1996.²² Because of this varying incubation period, AIDS no longer is a measure of a consistent segment of the HIV-infected population.

DATA FROM HIV SEROSURVEYS

In the late 1980s, the Department of Health conducted serosurveys and special studies to estimate the prevalence of HIV in various populations. Methods for conducting serosurveys and details of the surveys have been reported elsewhere.²⁴ Populations surveyed included persons attending STD and tuberculosis (TB) clinics, prisoners, women attending selected abortion and family planning clinics, sentinel hospitals (as part of a CDC national sentinel survey), and newborns tested at birth

(in the Survey of Childbearing Women by the New York State Department of Health).²⁰⁻²⁵ HIV reporting initiated in June 2000 has now supplemented the data from these surveys.

In nearly all of the serosurveys, HIV seroprevalence has declined since 1990 for both genders, all age groups, all race/ethnicity categories, and persons with all risk exposures. The overall prevalence in the STD clinic network was 9% in 1990, but had dropped to 4% in 1999. Dramatic declines in prevalence among injecting drug users (50% to 21% between 1991 and 1997) and men who have sex with men (47% to 17% between 1990 and 1999) have occurred.

However, there remain pockets of continued high seroprevalence. Prevalence in women entering the New York City correctional system is 18%, and it has been stable at that rate since it was first measured in 1989. Women entering treatment for noninjecting drug use have an equally high prevalence (18%); more disturbing is the observation that the prevalence among these women is three times higher than that in their male counterparts. Young men who have sex with men and who were surveyed in 1998–2000 in public locations have an overall prevalence of 17%, with 33% of this number young black men and 16% young Hispanic men.²⁶

THE NEXT DECADE: HOW NEW YORK CITY CAN BEST MONITOR HIV

Now that HIV in New York City has entered an endemic stage, changes are unlikely to be as widespread across the city and as dramatic as in the late 1970s and early 1980s. Subtle rises in HIV prevalence in small groups will not be easy to recognize. Surveillance data (AIDS and HIV reports, mortality reports) may not be sensitive enough to describe improvements in prevention in small groups at high risk for infection. Who is on the leading edge of the HIV epidemic? What are their demographic characteristics, and what are their risk factors?

HIV Incidence

Prevalence surveys include persons with infection of varying duration, reflecting infections that may be months or years old. To characterize persons recently infected, it is necessary to evaluate incidence. The New York City Department of Health has conducted incidence studies to follow the rate of HIV seroconversion over time in initially uninfected persons attending STD clinics.

This method of measuring incidence has now been supplemented by a new laboratory technique that makes it possible to use a single blood specimen to estimate incidence rates. This technique, known as the Serologic Testing Algorithm for Recent HIV Seroconversion (STARHS) or the “detuned assay,”²⁷ compares the results of the highly sensitive enzyme immunoassay, the test routinely used to detect HIV antibody, with results from a less-sensitive version of the same test. People with early-stage HIV (17–129 days after initial infection) test positive on the highly sensitive enzyme immunoassay, but negative on the less-sensitive detuned test. The combination of the two test results provides an estimate of the proportion of HIV-infected persons who seroconverted within the past 129 days. It is possible to characterize newly infected persons with respect to demographic characteristics and risk factors. This can tell us who among newly diagnosed persons are most likely to be recently infected, which can greatly facilitate prevention planning.

Although STARHS is currently approved for research purposes only, it may soon be available for routine use as a supplemental HIV test. While its clinical use

is being debated, the test may be valuable to monitor trends over time in characteristics of newly diagnosed HIV-infected persons who have a STAHRS test indicating recent infection. The New York City Department of Health intends to seek permission from physicians and patients to retest HIV-positive blood samples with STARHS, to provide the results (a potentially valuable counseling tool), and to interview persons tested about their risk factors.

HIV Reporting

In 2000, New York State implemented an HIV reporting law, and in the first year, 10,885 persons with prevalent and newly diagnosed HIV who do not have AIDS were reported to the New York City Department of Health. Additional cases of prevalent HIV infection are under investigation. HIV reporting is new to New York, and the New York City Department of Health is working through a large volume of preliminary reports of persons in care with HIV infection. It is hoped that HIV reporting will supplement information from AIDS case reporting, serosurveys, incidence studies, and mortality statistics.

Refining Use of AIDS Surveillance Data

As HIV reporting becomes routine, ongoing surveillance for AIDS can be used to characterize persons not in care. Persons who have an AIDS-defining condition, especially an opportunistic infection, at the time of first HIV diagnosis can be assumed not to have been in care and to have been unaware of their HIV infection. Opportunistic infection as a first diagnosis is more common in women, injecting drug users, and black and Asian New Yorkers, and the proportion of persons presenting with opportunistic infection increases with age (New York City Department of Health, unpublished data, June 2001). Overall, 30% of persons with AIDS in New York City have an opportunistic infection at the time of first report of AIDS. For just over half of those individuals, there is no evidence that HIV infection had been previously diagnosed. If the median latent period between seroconversion and AIDS is 10 years, persons who remain untested and hence not reached by interventions to reduce viral load and behavioral risks may be more likely to transmit their infections for as long as a decade before they are identified. The number of persons with HIV infection first diagnosed with an opportunistic infection suggests that a substantial minority of new HIV infections remain undetected until HIV-related illness occurs.

MONITORING PREVENTION: CHALLENGE FOR THE NEXT QUARTER CENTURY

The surveillance programs in place during the last 20 years have documented major successes in HIV prevention. Prevention measures such as blood supply screening; decline in needle sharing and needle exchange; safer sexual practices, including use of barrier protection; and zidovudine (ZDV) prophylaxis for pregnant women, have resulted in changes easily observed through surveillance data: the downturn in AIDS in white men who have sex with men and IDUs; the absence of new cases of AIDS associated with blood products/transfusions, the decline in the number of HIV-infected children, and the low HIV incidence in IDUs over the past decade.^{3,21,28}

Recent advances in antiretroviral therapy have lengthened survival in persons with HIV and delayed progression from HIV infection to AIDS. However, progression to AIDS continues, as evidenced by the rising number of New Yorkers diag-

nosed and living with AIDS (Fig. 2). The availability of effective therapy presents new public health challenges and roles for surveillance. It is increasingly important to identify all HIV-infected individuals so they can obtain effective antiretroviral therapy, and to focus HIV prevention measures on these seropositive individuals who constitute the reservoir of HIV. Every encounter of an HIV-infected person with the health care system should be taken as an opportunity to offer individualized prevention counseling, tools (condoms, syringes), partner notification and testing, and other means of interrupting transmission, including compliance with antiretroviral therapy and continued application of safe practices in sex and drug use.

HIV and AIDS surveillance has had proven benefit in characterizing persons at risk for HIV and will have an important role in years to come in focusing attention and evaluating success in prevention and care for HIV-infected persons in New York.

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