Trends From an HIV Seroprevalence Study Among Childbearing Women in New York State From 1988 Through 2000

A Valuable Epidemiologic Tool

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Background: Women in New York State are heavily affected by the human immunodeficiency virus (HIV) epidemic. New York has had the largest number of births to HIV-infected pregnant women in the United States. Data collected as part of the Survey of Childbearing Women have been valuable for assessing the impact of the disease on the women of New York.

Objective: To assess HIV prevalence trends among childbearing women in New York State.

Design, Setting, and Participants: An unlinked HIV seroprevalence study was conducted among all women residing in and giving birth in New York State from 1988 through 2000. Trend and cohort analyses were conducted.

Main Outcome Measure: HIV prevalence, defined as the number of HIV-positive specimens divided by the total number of HIV-positive and HIV-negative specimens, by geographic region, racial/ethnic group, and maternal age cohort.

Results: Trends indicated a steady decline in HIV prevalence in New York State. New York City had a 49% decrease in prevalence between 1988 through 1989 and 1999 through 2000, and the rest of the state showed a 24% decline. However, birth cohort analysis indicated different patterns in trend by subpopulation, with some groups experiencing little or no decline.

Conclusion: This study reports on the only statewide population-based HIV prevalence data currently available for childbearing women; these data have been a valuable tool for monitoring trends, targeting resources, and evaluating programs and policies.


INFECTION WITH HUMAN IMMUNODEFICIENCY virus (HIV) has increasingly occurred among women of childbearing age, with New York State (NYS) having a larger proportion of HIV-infected women and children than the rest of the country, largely as a result of the large epidemic among intravenous drug users. In November 1987, the NYS Department of Health began monitoring the HIV epidemic among childbearing women with the implementation of the Survey of Childbearing Women. This was a blinded (no identifying information was linked to the survey data) HIV seroprevalence survey in which heel-stick blood spot specimens from all infants born in NYS were tested for HIV antibodies by the state Newborn Screening Program. From 1988 to 1995, the US Centers for Disease Control and Prevention, Atlanta, Ga, funded similar studies in most states. The last Centers for Disease Control and Prevention report that included data from the Survey of Childbearing Women (1994 data) showed NYS as having the largest number of births to HIV-infected pregnant women in the United States. In NYS, the survey was continued with state funding because of the valuable data it generated.

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The protocol changed in May 1996 when state regulations required that all women delivering be given the opportunity to consent to receive the results of the blinded newborn HIV test. Specimens from infants whose mothers consented to receive the newborn HIV test results were tested with identifiers and the remaining specimens tested blindly. The protocol changed again in February 1997 with the implementation of state legislation requiring HIV testing, with identifiers, of all newborns with the results reported back to the hospital of birth for transmittal to the pediatrician of record. Throughout these program changes, the survey data have re-
mained consistent since 1988, allowing the ability to monitor trends in HIV prevalence in the population of childbearing women in NYS across more than a decade. Early results from the Survey of Childbearing Women showed that the magnitude of the HIV epidemic in NYS childbearing women far exceeded previous estimates. This information prompted the state health department to launch major new initiatives in HIV prevention and care aimed at childbearing women and children. The data continued to be useful across time in targeting resources and evaluating programs.

This article analyzes HIV prevalence among childbearing women in NYS from 1988 through 2000 to assess changes in prevalence in different populations. These data continue to be valuable for targeting prevention efforts into the third decade of the epidemic and are the only continuous population-based data on HIV prevalence among childbearing women in the United States.

METHODS

All newborns in NYS have a heel-stick filter paper blood specimen collected for screening of inborn errors of metabolism and HIV-antibody testing. For this study, childbearing women are the unit of analysis. Because of cross-placental transfer of antibodies, the HIV antibody in a newborn's blood specimen represents the antibody status of the mother. In this study, specimens from infants who survived to provide a suitable initial specimen for testing by the Newborn Screening Program were analyzed (repeated or follow-up specimens and the specimens of the second or subsequent infants in multiple births were not assessed). Newborn HIV test results reflecting the HIV infection status of more than 96% of women delivering babies in NYS during this period were included in the analysis. The demographic data collected by the birth facility and transmitted to the state health department on the newborn screening specimen collection form include month and year of delivery, maternal age at the time of delivery, race/ethnicity, and county and zip code of residence. A total of 3.43 million infants were tested for HIV antibodies during the 13-year period studied (January 1988-December 2000).

TRENDS ANALYSIS

The annual HIV prevalence among childbearing women was calculated as the number of HIV-positive specimens divided by the total number of HIV-positive and HIV-negative specimens each year. As in any study repeatedly measuring prevalence in a population across time, data from the same individual women are undoubtedly represented in the prevalence estimates for more than 1 year. Because it is unlikely that individual women would become pregnant and deliver twice in one calendar year, the prevalence estimates we report probably accurately represent the annual HIV seroprevalence among childbearing women in the state. Race/ethnicity was divided into mutually exclusive categories of white, African American, Hispanic, Asian/Pacific Islander, Native American, and other. Analysis was also conducted by region of residence, based on zip code, and grouped into the following regions: New York City (NYC) and its boroughs, and the rest of the state and its subsections, which are NYC vicinity, including the 4 counties (Nassau, Rockland, Suffolk, and Westchester) surrounding NYC; mid-Hudson, including Orange, Sullivan, Ulster, Putnam, and Dutchess counties; upstate urban, including Albany, Schenectady, Onondaga, Monroe, and Erie counties; and upstate rural, consisting of the remaining counties.

The annual HIV seroprevalence of childbearing women was assessed for each racial/ethnic subgroup within NYC and the rest of NYS across time for each year from 1988 through 2000. The change in prevalence was evaluated by comparing the HIV prevalence for the first 2 years (1988-1989) and last 2 years (1999-2000) of the study for each racial/ethnic subgroup within each borough in NYC and each of the 4 regions outside of NYC. The relative risk and 95% confidence intervals were used to determine if there was a statistically significant change in prevalence during the 2 periods for each subgroup examined using the 1988 through 1989 period as the referent group.

MATERNAL BIRTH COHORT ANALYSIS

To assess changes in HIV prevalence across time within different maternal birth cohorts, women were grouped by year of birth rather than age at time of delivery. A birth cohort analysis was conducted for the racial/ethnic and geographic subgroups that had a sufficient number of observations. The women were grouped into 5-year birth cohorts beginning with the 1950-1954 cohort and ending with the 1980-1984 cohort. For each cohort, the trend in annual HIV prevalence was assessed for the period 1988 through 2000 in 2 ways.

First, the HIV prevalence for each cohort in each year of the study was plotted across the average age of the cohort at the time of delivery. For example, the prevalence for women in cohort 1965-1969 in 1988 was plotted at age 21 and the prevalence for women in the same birth cohort who delivered in 2000 was plotted at age 33.

A second analysis was made in which the HIV prevalence of each cohort was compared with the prevalence of the preceding (next older) cohort for the years in which their ages overlapped. For example, the prevalence for women in the 1970-1974 cohort was calculated for the years 1993 through 2000 when they were 19 to 30 years of age and compared with the HIV prevalence of the women in the 1965-1969 cohort for the years 1988 through 1995 when they were the same age (also 19-30 years of age). To examine differences between cohorts, relative risk and 95% confidence intervals were calculated for each cohort comparison using the earlier cohort as the referent group.

RESULTS

In general, there has been a steady decline in HIV prevalence among childbearing women in all racial/ethnic subgroups in NYC and the rest of the state (Figure 1). In NYC, the HIV prevalence declined 49% from 1.22% in 1988 through 1989 to 0.62% in 1999 through 2000 with a relative risk of 0.51 (95% confidence interval, 0.48-0.54) (Table). The number of HIV-positive women giving birth to live infants in NYC dropped from an average of 1523 per year in 1988 through 1989 to 721 per year in 1999 through 2000. For all NYC women, the percentage decline was greatest among white women, followed by Hispanic and African American women. The decrease in prevalence was seen in all boroughs and most of the racial/ethnic subgroups in each borough (data not shown). However, the decrease was not uniform within all subgroups, with African American women from the Bronx showing the smallest decline.

Outside of NYC, there was an overall decrease of 24% from 1988 through 1989 to 1999 through 2000 (rela-
tive risk, 0.74; 95% confidence interval, 0.64-0.84). Nearly all of the overall decrease in prevalence in Upstate New York was a result of the declines in HIV prevalence in the NYC vicinity and mid-Hudson regions (data not shown). There was no significant decline in upstate rural areas and a small, nonsignificant increase in upstate urban areas (Table).

MATERNAL BIRTH COHORT ANALYSIS

Figure 2 shows an example of the cohort plots used to assess trends in the annual HIV prevalence from 1988 through 2000 for each maternal birth cohort by maternal age at the time of delivery. With the exception of the 1980-1984 birth cohort, each trend line includes 13 data points with the first point representing the HIV prevalence among childbearing women in 1988 and the last point representing 2000. The 1980-1984 birth cohort trend line includes only 9 data points representing the maternal HIV seroprevalence from 1992 through 2000. As apparent from Figure 2A, the overall decrease in HIV prevalence from 1988 through 2000 among NYC childbearing women was due in part to 3 contributing factors: (1) Each successive 5-year age cohort had a lower HIV prevalence at a comparable age (for example, those in the 1980-1984 maternal birth cohort who gave birth in 2000 were 16-20 years of age and had a seroprevalence rate of 0.25%, whereas those in maternal birth cohort 1975-1979 who gave birth in 1995 while they were 16-20 years of age had a seroprevalence rate of 0.45%, and those in the 1970-1974 birth cohort who gave birth in 1990 when they were 16-20 years of age had a seroprevalence rate of 0.65%). (2) Beginning around 1990, there was steep decline in HIV prevalence among most of the older cohorts born during or prior to the period 1965-1969. (3) Among many of the younger cohorts born after the 1965-1969 cohort, the HIV prevalence increased with increasing age but peaked at an age-specific HIV prevalence lower than their previous cohorts before leveling out or decreasing.

The cohort patterns differed substantially between subpopulations experiencing little or no overall decline in prevalence and those experiencing significant decline. Figure 2B portrays the cohort pattern for African American childbearing women in the Bronx, a subpopulation that experienced little decline in prevalence. For this racial group, each of the younger birth-year cohorts followed the same trend as its preceding cohort and peaked at an age-specific prevalence similar to that of its preceding cohort. In addition, the older cohorts did not experience the sharp declines in prevalence seen in all NYC women.

To quantify this difference in cohorts, a comparison was made between each cohort and its preceding cohort for the points that their ages overlapped (1988-1995 and 1993-2000). In this analysis of trends across time in NYC and the rest of the state, the HIV prevalence was lower for the most recent birth cohort; the trend toward reduced prevalence across time was statistically significant in all but one comparison (in childbearing women outside of NYC, those in the 1950-1954 birth cohort had a higher seroprevalence than that of the 1945-1949 birth cohort). The greatest difference in prevalence was seen between the 1965-1969 and 1970-1974 birth cohorts in NYC and between the 1950-1954 and 1955-1959 birth cohorts in upstate New York (data not shown but available on request).

This study reports on the only statewide, population-based HIV prevalence data for childbearing women currently available in the United States. Similar to other HIV seroprevalence studies in key target populations, this study documents continued significant declines in HIV prevalence. However, unlike most studies, this study includes complete data on an entire population since 1988, allowing for an analysis of racial/ethnic and geographic subpopulations, some of which showed little or no decreasing HIV prevalence. Significant declines in HIV prevalence among childbearing women have occurred in most, but not all, subgroups of women studied. Overall, there was a 49% decline among women in NYC and 24% among women living outside NYC. White and Hispanic women experienced the greatest declines in NYC (68% and 61%, respectively). African American women in NYC also experienced a decline in prevalence (31%) but not as great a decline as that seen in white and Hispanic women. Outside NYC, Hispanic and African American women (73% and 37%, respectively) also experienced declines, with white women showing the smallest decline (17%).

The maternal birth cohort analysis indicates 3 factors contributing to the overall declines: (1) a lower HIV prevalence in women of comparable ages among subsequent birth cohorts; (2) declines in prevalence across time among women in the older birth cohorts; and (3) a peaking of age-specific HIV prevalence among the younger cohorts at a level below that of their preceding cohort. Subpopulations experiencing 1 or more of these patterns tend to show a substantial decrease in the overall HIV prevalence across time. While many geographical and racial/ethnic subpopulations showed these favorable trends, not all did. In particular, African American women living in the Bronx and upstate rural women showed little or no decline in HIV seroprevalence across time. In those subpopulations, the trends in HIV prevalence were stable or even increasing slightly across time. The younger cohorts showed increasing prevalence across time, following the same trend and reaching the same peak level of age-specific prevalence as their preceding cohorts. In addition, the older cohorts in these subpopulations did not show a substantial decline in HIV prevalence across time.

Data from this study are too limited to determine what factors are responsible for the decreasing trends seen. Factors that may contribute to these decreasing trends include the following: (1) Prior to the widespread use of highly active antiretroviral therapy, the older cohorts of HIV-infected women likely were experiencing premature death or difficulty in conceiving and/or carrying an infant to term because of HIV infection or comorbidities. (2) The initial cohort of women infected with HIV in the late 1970s and early 1980s through intravenous drug use was aging beyond the childbearing years. (3) There may have been an increase in high-prevalent populations migrating out of the state or low-prevalent populations migrating into the state; however, we have no data to support this. Actually, our array of services for persons with HIV in New York may lead to the opposite effect. (4) Because the number of women living with HIV in NYS is increasing because of improved therapies, a much smaller proportion of them are actually delivering live infants. Women with HIV may intentionally be opting not to conceive or carry to term if they become pregnant; in 2000, 90% of HIV-infected women giving birth knew their HIV status prior to delivery, up from 77% in 1997. Women giving birth since 1997 know their HIV status as a result of newborn testing; this suggests indirectly that fewer women were becoming pregnant not knowing their HIV status. 5) Finally, there may be a decrease in the number of childbearing women becoming infected, an indication that HIV prevention efforts are working.

An important factor that may explain decreasing prevalence is that prevention efforts aimed at minority populations in high-seroprevalence geographic areas are successfully affecting women in NYS. Early results of the Survey of Childbearing Women quantified the magnitude of the HIV epidemic among childbearing women and their infants in NYS. This prompted the NYS Department of Health AIDS Institute to direct resources to develop new initiatives targeting high-risk populations.

- Beginning in 1989, grants were developed to provide hospital-based pediatric and maternal HIV comprehensive services at high-prevalence hospitals.
- Following the results of the Pediatrics AIDS Clinical Trial Group 076 trials in 1994, 7 the Maternal and Pediatric HIV Care Program was established in NYS with the goal of reducing perinatal transmission to the lowest possible level through prenatal HIV testing and preventive therapy.
- Detailed clinical treatment guidelines for antiretroviral therapy and prevention of perinatal transmission.
tion were published, and extensive training of physicians, nurses, and ancillary personnel was conducted.

- A network of specialty providers for perinatal HIV medical care was established, including 50 health care facilities and family planning clinics in high-prevalent areas, for HIV counseling and testing of pregnant women and medical care and support services for those whose test results are positive for HIV.

- More recently, the data on HIV seroprevalence among childbearing women have been used to develop an initiative targeting high-seroprevalence zip codes in upper Manhattan, South Bronx, Central Brooklyn, and Erie County (Buffalo). This initiative began in 1999 and is called Community Action for Prenatal Care. This initiative uses high-intensity training outreach efforts targeting homeless, substance using, and mentally ill women in these zip codes to engage them in whatever care and services are needed to meet their immediate needs (housing, substance use treatment, mental health services) including primary health care and obstetric/gynecologic care. Most of these women are in minority groups. Seroprevalence data on childbearing women were used not only to target this initiative but also to evaluate its effect.

- Survey of Childbearing Women data are also used as a key parameter in the state health department’s Community Need Index, a statistical compilation of factors that scores each zip code in the state on the basis of HIV risk. The index is used to justify allocation of resources in periodic reprocurement of state HIV prevention and care initiatives.

Human immunodeficiency virus infection in childbearing women has important public health ramifications. It not only affects the women but their children as well. In the United States, 90% of the pediatric AIDS cases reported in the period 1996 through 1999 were attributable to perinatal transmission. Decreasing the prevalence of HIV in childbearing women benefits childbearing women as well as their children.

Our study provides trend information on HIV prevalence among childbearing women across 13 years. It has shown that HIV prevalence in this population is declining in NYS but that specific subgroups have not seen a decline. The information allows for better targeting of HIV prevention and outreach services.

Throughout this period, significant declines in HIV prevalence have been observed in New York among childbearing women. In addition, there have been dramatic decreases in the number of deaths due to AIDS in NYS. The availability of highly active antiretroviral therapy may lead some HIV-infected women to decide to become pregnant because of a more positive outlook for their own health and because, coupled with the use of zidovudine, the therapy reduces vertical transmission, resulting in a potential reversal of the observed downward trends in maternal HIV prevalence among childbearing women. Thus, the continued decrease in prevalence is even more remarkable because of this possibility that more women who know their HIV status may be electing to have children. While this is not yet evident in our data, continued use of this epidemiologic surveillance tool will be important to monitor any reversal in the trends in HIV prevalence.

This study had some limitations. The unlinked nature of the data limits the ability to identify individuals, and therefore, it is not possible to assess HIV incidence or unduplicate HIV-positive women who deliver on multiple occasions. We cannot tell the magnitude of their effect but it is likely to be low and the seroprevalence does reflect the seroprevalence of childbearing women in a given year. In addition, while data from individual women may appear in more than 1 year, the effect of any woman becoming pregnant and delivering twice in any calendar year would be very small. The limited number of variables available for analysis and the fact that the data were collected by personnel in each birth facility and not by dedicated study staff also hinders interpretation. We were unable to determine regions of high HIV prevalence more specifically than zip code level. Race/ethnicity information is based on broad self-reported information. The data may not be applicable outside NYS but the method should be of interest to all.

The Survey of Childbearing Women has proven to be a valuable epidemiologic tool for assessing the magnitude of the HIV burden among subpopulations of childbearing women in NYS as well as following trends in these populations. The data generated from this study have been used extensively in targeting resources and evaluating programs and policies directed at this population. Although the information collected through this study is too limited to make causal inferences between observed trends and specific prevention efforts, it has been extremely valuable in highlighting areas and subpopulations where overall prevention efforts appear to be working or are in need of improvement. These data will continue to be used to evaluate and target HIV prevention efforts and serve as an early warning of changes in populations at risk as the epidemic continues to evolve.

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