Continuum of Care Among People Living with Perinatally Acquired HIV Infection in New York City, 2014

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ABSTRACT

Objective. The HIV care continuum outlines the steps from HIV infection to diagnosis, linkage to care, and viral suppression among people living with HIV. We examined data for steps along the HIV care continuum among people living with perinatally acquired infection in New York City using surveillance data.

Methods. This study included data for people who acquired HIV infection perinatally and lived in New York City as of December 31, 2014. We defined "in care" as having ≥1 CD4 or viral load test in 2014, "in continuous care" as having ≥2 CD4 or viral load tests ≥3 months apart in 2014, and "virally suppressed" as having a viral load of ≤200 copies per milliliter in the most recent test in 2014. We estimated factors associated with viral suppression from a weighted log-binomial regression model that included sex, race/ethnicity, age, and country of birth as independent variables.

Results. As of December 31, 2014, an estimated 1,596 people were living with perinatally acquired HIV infection in New York City. All were diagnosed, 96% were in care, 80% were in continuous care, and 61% were virally suppressed. The multivariable analysis showed significant differences in viral suppression by race/ethnicity and age. Black patients (59%, 534/907) were the least likely of all racial/ethnic groups examined to have a suppressed viral load. By age, compared with 73% (80/109) of children aged 0–12 years who were virally suppressed, 58% (568/987) of adults aged 20–29 years and 56% (54/96) of adults aged 30–39 years were virally suppressed; the adjusted prevalence ratio was 0.80 (95% confidence interval [CI] 0.69, 0.92) for those aged 20–29 years and 0.79 (95% CI 0.63, 0.99) for those aged 30–39 years.

Conclusion. The low level of viral suppression among people living with perinatally acquired infection found in this study warrants further exploration to identify the best management strategies to improve viral suppression in this population, especially those transitioning from pediatric to adult health care.

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The human immunodeficiency virus (HIV) care continuum, sometimes referred to as the HIV treatment cascade, outlines the steps from initial HIV infection to diagnosis, linkage to care, retention in care, and viral suppression among people living with HIV (PLWH).[1–4] This model has been used by federal, state, and local agencies to identify gaps in diagnosis and care and to develop strategies for improving outcomes.[5–8] The Centers for Disease Control and Prevention (CDC) reported that among 1.2 million PLWH in the United States at the end of 2011, 81.9% had been diagnosed, 65.8% had been linked to care, 36.7% had been retained in care, 32.7% had been prescribed antiretroviral treatment (ART), and 25.3% had a suppressed viral load (defined as ≤200 copies per milliliter [mL]). The report identified substantial differences in each step of the HIV care continuum among various subpopulations. For example, among adults aged 25–34 years, 28% were in care and 15% were virally suppressed, while among adults aged 55–64 years, 46% were in care and 36% were virally suppressed. Proportions of viral suppression were higher among white PLWH (30%) than among Hispanic (26%) and black (21%) PLWH.[5]

The HIV care continuum is also used to describe HIV care outcomes in some at-risk populations, including men who have sex with men (MSM), transgender individuals, injection drug users, and female sex workers.[5,9–13] Among MSM living with diagnosed HIV infection in the United States in 2010, 77.5% had been linked to care, 50.9% had been retained in care, 49.5% had been prescribed ART, and 42.0% were virally suppressed. Younger MSM had lower levels of retention in care than older MSM: 45.7% of 18- to 24-year-olds and 47.7% of 25- to 34-year-olds compared with 52.0% of 45- to 54-year-olds and 53.5% of those aged ≥55 years were retained in care. Younger MSM also had lower proportions of viral suppression than older MSM: 25.9% of 18- to 24-year-olds and 32.2% of 25- to 34-year-olds compared with 45.3% of 45- to 54-year-olds and 60.8% of those aged ≥55 years were virally suppressed. Black MSM had the lowest level of retention in care (46.3%) compared with Hispanic (54.1%) and white (52.1%) people, and the lowest proportion of viral suppression (37.0%) compared with Hispanic (41.5%) and white (43.9%) people.[9]

One population missing in such analyses is people living with perinatally acquired HIV infection. CDC estimated that by the end of 2011, 10,541 people who had acquired HIV infection perinatally were living in the United States.[14] Some of them were born before the availability of ART and were adults in 2011; others were born after the availability of ART but received treatment only after their CD4 counts dropped below a certain threshold (200 copies/mL in the 2003 U.S. Department of Health and Human Services ART guidelines, 350 copies/mL in the 2007 guidelines, and 500 copies/mL in the 2009 guidelines); still others were born recently and initiated ART immediately after diagnosis (2012 guidelines recommended initiating treatment to all HIV-infected people regardless of CD4 count).[15–17] People living with perinatally acquired HIV infection face unique challenges,[18,19] including long histories of treatment and extensive drug resistance, making it difficult to identify effective regimens and to achieve and maintain viral suppression.[20,21] The purpose of this analysis was to describe surveillance data on the HIV care continuum among people living with perinatally acquired infection in New York City.

METHODS

Data source

We used data from the New York City HIV surveillance registry. Acquired immunodeficiency syndrome (AIDS) diagnoses have been reportable in New York State since 1981. In 2000, New York State law expanded AIDS case reporting to include diagnoses of non-AIDS HIV infection.[22] All CD4 and viral load values and nucleotide sequences obtained for genotypic analyses have been reported to the registry since June 1, 2005. As of December 31, 2014, the registry contained data on a cumulative total of more than 220,000 cases (both alive and dead) and more than 8 million laboratory tests.

Study population

The study population included people who acquired HIV infection perinatally in New York City or elsewhere and lived in New York City as of December 31, 2014. Data on patients' perinatal transmission risk were reported by medical providers using the New York State medical provider report forms or collected by surveillance field staff members through medical record abstractions. Patients who were born to HIV-infected mothers and diagnosed with HIV infection after birth were confirmed perinatal cases, and patients who were born to mothers of unknown HIV status and diagnosed with AIDS or HIV infection at ≤12 years of age were presumed to be perinatal cases after other transmission risks were excluded. The analysis included data on people with confirmed and presumed perinatal infection.

The statistical weighting method to estimate the number and characteristics of people living with HIV in New York City, including in-care patients who had at least one CD4 or viral load test and out-of-care

patients who had no CD4 or viral load tests in 2014, is described elsewhere.[23,24] Briefly, patients included in the study population were weighted according to their probability of receiving HIV care in New York City. In-care patients were those who had at least one CD4 or viral load test in New York City in 2014, and out-of-care patients were estimated from in-care patients who were previously out of care but returned for care in 2014.

Weighted analyses are used in population-based surveys when respondents have a known, non-zero, unequal probability of selection.[25,26] In these analyses, each participant is given a weight and unequal selection probability is accounted for. Those who were less likely to respond to the survey and therefore were underrepresented in the final dataset received greater weight, and nonrespondents were represented by those with similar characteristics who did respond. We treated the New York City HIV laboratory data reporting system as if it were a special annual population-based survey that ran from January 1 to December 31. Every patient in New York City had a non-zero, unequal probability of participating in this survey, because all HIV patients would eventually seek care given the natural history of untreated HIV, and patients with sporadic care would be less likely to receive care in any given year than patients with regular care.[27]

Patients who had at least one CD4 or viral load test in 2014 were considered participants in the annual survey. Each participant was then given a weight equal to the inverse of the probability that a patient had a CD4 or viral load test in New York City in 2014. We determined the probability by calculating the time between the last care visit before 2014, or the date of diagnosis if no care visits were made before 2014, and the first care visit in 2014.[28] If the time between a patient's last care visit before 2014 and his first care visit in 2014 was ≤1 year—meaning that the patient was in regular care and definitely included in the 2014 sample with a probability of 100%—the patient received a weight of 1. If a patient was either (*1*) newly diagnosed in New York City in 2014 or (*2*) previously diagnosed outside of New York City, moved into New York City in 2014, and received his first care visit in New York City in 2014, the patient also received a weight of 1. If the time between a patient's last care visit before 2014 and first care visit in 2014 was >1 year, the patient received a weight equal to the time interval in years. For example, if a patient had his last care visit exactly three years before his first care visit in 2014, he received a weight of 3, and the patient not only represented himself, but also two out-of-care patients.

We then split all records with a weight >1 into two records, one with a weight of 1 representing the patient and the other with the weight minus 1 representing out-of-care patients. In the previous example, the patient with a weight of 3 would be split into two records: one with a weight of 1 and a status of in care representing the patient, and the other with a weight of 2 and a status of out of care representing two out-of-care patients. Patients who had at least one CD4 or viral load test in 2014 but died in 2014 were removed from the analysis. However, when a patient had a weight >1, meaning he also represented out-of-care patients, the corresponding out-of-care patient records were retained in the dataset. By splitting the records, we were able to estimate the number and characteristics of both in-care and out-of-care patients in one dataset.

HIV care continuum

We defined "HIV infected" as people who acquired HIV infection perinatally in New York City or elsewhere and were living in New York City as of December 31, 2014; "diagnosed" as people who had ever been diagnosed with perinatally acquired HIV infection; "in care" as having ≥1 CD4 or viral load test in 2014;[29–31] "in continuous care" as having ≥2 CD4 or viral load tests ≥3 months apart in 2014;[30–33] and "virally suppressed" as having a viral load value ≤200 copies/mL in the most recent test in 2014.[34,35]

Because the New York City HIV registry does not contain clinical encounter information, and because CD4 and viral load tests are a good proxy for HIV care,[36] we used the presence of any CD4 or viral load test reported to the New York City Department of Health and Mental Hygiene to indicate a care visit. The definition of "retention in care" varies in the medical literature and in research and public health communities.[31] New guidelines recommending less frequent monitoring among stable patients led us to adopt the single-visit definition of "in care."[16,37] Because the two-visit definition is widely used, we also reported patients as being "in continuous care" if they had ≥2 CD4 or viral load tests ≥3 months apart in 2014. The two CD4 or viral load tests could be two CD4 counts, two viral load tests, or one CD4 count and one viral load test performed during the year at least three months apart.

We calculated the number of HIV-infected patients as the number of diagnosed patients divided by the estimated percentage of people living with perinatally acquired HIV infection in New York City in 2014 who had been diagnosed, and we assumed that all people who were infected were diagnosed. This assumption was based on (*1*) pregnant women are routinely screened for HIV, including those in labor whose HIV status is unknown; (*2*) since 1988, the New York State Department of Health has tested all newborns for

serologic evidence of maternal HIV infection, initially as a blinded serosurvey and, since 1997, through the Newborn Screening Program;[38] and (*3*) since 2006, no child born in New York City and diagnosed with perinatally acquired HIV infection in New York City had a diagnosis date more than six months after birth. We estimated diagnosed patients using the aforementioned weighting method. We obtained data on patients who were in care, in continuous care, and virally suppressed from the New York City HIV registry.

Statistical analysis

We first described the number and characteristics of people living with perinatally acquired HIV infection in New York City as of December 31, 2014. We described the HIV care continuum for the overall population and by sex, race/ethnicity, age, and country of birth. To assess the factors associated with viral suppression, we estimated adjusted prevalence ratios and 95% confidence intervals (CIs) from a weighted log-binomial regression model that included sex, race/ethnicity, age, and country of birth as independent variables. The model did not include time since infection or diagnosis because such time equals age for these perinatal patients, and the model included age. We ran all analyses using SAS® version 9.3.[39]

RESULTS

In 2014, 1,535 people living with perinatally acquired HIV infection in New York City received at least one CD4/viral load test and were considered in-care patients. Of these, 109 people were previously out of care and returned for care in 2014. These 109 patients represented themselves as well as 61 out-of-care patients. In total, 1,596 (1,535 + 61 = 1,596) people were living with diagnosed perinatally acquired HIV infection in New York City.

More females than males (828 vs. 768) were included in this group, and most participants were black or Hispanic (1,515, 94.9%). The youngest person living with perinatally acquired HIV infection was born in 2014, and the oldest was born in 1978, diagnosed in 1987, and aged 36 years as of December 31, 2014; the mean (median) age was 21 (22) years. By stages of HIV care, 1,596 (100%) were diagnosed, 1,535 (96%) were in care, 1,278 (80%) were in continuous care, and 973 (61%) were virally suppressed. The 973 virally suppressed patients included 855 patients in continuous care and 118 patients not in continuous care. Black participants comprised the majority of patients (57%) but had the lowest proportion of viral suppression (59%) compared with other racial/ethnic groups (Table 1). The percentage of viral suppression was lowest among patients aged 22 years (54%, 61/114) and 23 years (53%, 76/143) (Figure).

The multivariable analysis found no differences in viral suppression by sex or country of birth, but did find significant differences by race/ethnicity and age (Table 2). Black patients (59%, 534/907) were less likely to have a suppressed viral load than patients who were white (75%, 46/61, p=0.01), Hispanic (62%, 376/608, p=0.07), or from other races (79%, 16/20, p=0.03). Compared with children aged 0–12 years, in which 73% (80/109) were virally suppressed, viral suppression was lower in those aged 20–29 years (58%, 568/987) and 30–39 years (56%, 54/96), with adjusted prevalence ratios of 0.80 (95% CI 0.69, 0.92) and 0.79 (95% CI 0.63, 0.99), respectively.

DISCUSSION

Patients in our study had high proportions of HIV diagnosis (100%), retention in care (96%), and viral suppression (61%). We found no differences among our study population in percentage retained in care or viral suppression by sex or country of birth; however, percentages of virally suppressed patients differed significantly by race/ethnicity and age group.

Compared with approximately 80,000 people living with diagnosed non-perinatally acquired HIV infection in New York City, people living with perinatally acquired HIV infection had a higher percentage of retention in care (96% vs. 91%) but a lower percentage of viral suppression (61% vs. 72%).[23] The lower percentage of viral suppression may have been caused partially by the larger percentage of young people in the perinatal population than in the non-perinatal population.[6,30] Compared with older adults, young people living with HIV generally have poorer adherence to ART and a lower prevalence of viral suppression because of social, behavioral, and developmental factors (e.g., decreased parental support and oversight, experimentation with alcohol and other substances, and desire for risk taking).[21,40] Young people living with perinatally acquired HIV infection since birth or young age may have barriers (e.g., treatment fatigue) that are similar to those confronted by young patients living with cystic fibrosis or type I diabetes since birth or young age. The proportion of viral suppression among young people in New York City may have improved, however: the proportion of virally suppressed patients in our study population in 2014 (61%) was higher than the percentage (37%) of people living with perinatally acquired infection in 2009–2012 at 20 sites participating in the Adolescent Medicine Trials Network for HIV/AIDS Intervention.[41]

Table 1. Characteristics of people living with perinatally acquired HIV infection, New York City, December 31, 2014[a]

Characteristic	*Unweighted number*	*Number infected with HIV (weighted percent)[b]*	*Number diagnosed with HIV (weighted percent)[b]*	*Number in care (weighted percent of those diagnosed with HIV)[b,c]*	*Number in continuous care (weighted percent of those in care)[b,d]*	*Number virally suppressed (weighted percent of those in continuous care)[b,e]*
Total	1,536	1,596 (100)	1,596 (100)	1,535 (96)	1,278 (80)	973 (61)
Sex						
Male	730	768 (48)	768 (100)	729 (95)	594 (77)	464 (60)
Female	806	828 (52)	828 (100)	806 (97)	684 (83)	508 (61)
Race/ethnicity						
Black	868	907 (57)	907 (100)	867 (96)	728 (80)	534 (59)
Hispanic	588	608 (38)	608 (100)	588 (97)	486 (80)	376 (62)
White	60	61 (4)	61 (100)	60 (98)	46 (75)	46 (75)
Other	20	20 (1)	20 (100)	20 (98)	18 (88)	16 (80)
Age, in years						
Mean	21	21	21	21	21	21
Median	22	22	22	22	21	21
0–12	109	109 (7)	109 (100)	108 (99)	97 (89)	80 (73)
13–19	402	405 (25)	405 (100)	402 (99)	362 (89)	270 (67)
20–29	935	987 (62)	987 (100)	935 (95)	749 (76)	568 (58)
30–36	90	96 (6)	96 (100)	90 (94)	70 (73)	54 (56)
Country of birth						
United States	1,337	1,391 (87)	1,391 (100)	1,337 (96)	1,111 (80)	842 (61)
U.S. dependent areas[f]	34	34 (2)	34 (100)	34 (99)	28 (81)	18 (52)
Foreign-born	90	92 (6)	92 (100)	89 (97)	76 (83)	68 (45)
Unknown	75	79 (5)	79 (100)	75 (95)	63 (80)	45 (57)

[a]Data source: New York City HIV registry. New York City Department of Health and Mental Hygiene, 2015.

[b]Weights are rounded and sum may not equal to total because of rounding.

[c]In care: ≥1 CD4/viral load test in 2014

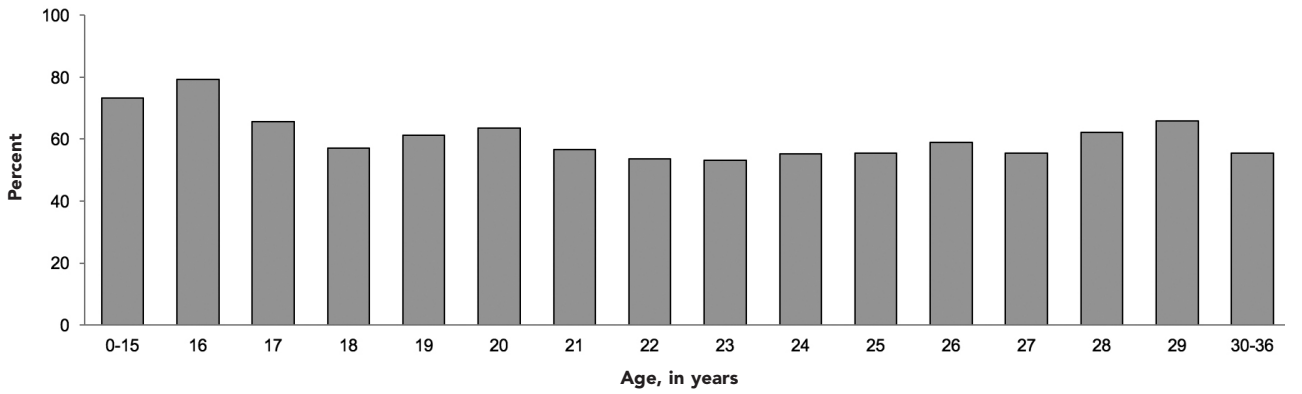
[d]In continous care: ≥2 CD4/viral load tests ≥3 months apart in 2014

[e]Virally suppressed: last viral load value in 2014 ≤200 copies per milliliter, including patients in continuous care and virally suppressed, and patients not in continuous care but virally suppressed.

[f]Dependent areas include American Samoa, Guam, the Northern Mariana Islands, Puerto Rico, the Republic of Palau, and the U.S. Virgin Islands.

HIV = human immunodeficiency virus

Figure. Percentage of people virally suppressed among people living with perinatally acquired HIV infection, New York City, 2014



[a]Data source: New York City HIV registry data. New York City Department of Health and Mental Hygiene, 2015.

[b]Virally suppressed is defined as having a viral load ≤200 copies per milliliter for most recent test in 2014.

HIV = human immunodeficiency virus

The low percentage of virally suppressed patients aged 20–29 years possibly relates to their exposure to non-highly active ART in the early 1990s and then serial protease inhibitor monotherapy or non-nucleoside reverse transcriptase inhibitor therapy in the mid-1990s; these therapies could lead to multidrug resistance and result in fewer current treatment options. Those born in the late 1990s and afterward likely received

Table 2. Characteristics associated with viral suppression among people living with perinatally acquired HIV infection, New York City, 2014[a]

Characteristic	*Number of people living with perinatally acquired HIV infection (weighted)*[b]	*Number of people virally suppressed*[c] *(percent)*	*Adjusted prevalence ratio (95% CI)*	P-*value*
Total	1,596	973 (61)		
Sex				
Male	768	464 (60)	Ref.	
Female	828	508 (61)	1.01 (0.93, 1.10)	0.77
Race/ethnicity				
Black	907	534 (59)	Ref.	
Hispanic	608	376 (62)	1.08 (0.99, 1.18)	0.07
White	61	46 (75)	1.21 (1.04, 1.40)	0.01
Other	20	16 (79)	1.28 (1.02, 1.60)	0.03
Age group, in years				
0–12	109	80 (73)	Ref.	
13–19	405	270 (67)	0.92 (0.80, 1.07)	0.30
20–29	987	568 (58)	0.80 (0.69, 0.92)	<0.001
30–39	96	54 (56)	0.79 (0.63, 0.99)	0.04
Country of birth				
United States	1,391	842 (61)	Ref.	
U.S. dependent areas[d]	34	18 (52)	0.83 (0.60, 1.16)	0.27
Foreign	92	68 (74)	1.12 (0.97, 1.30)	0.13
Unknown	79	45 (57)	0.94 (0.77, 1.14)	0.52

[a]Data source: New York City HIV registry data. New York City Department of Health and Mental Hygiene, 2015.

[b]Sums may not add to total because of rounding of weights.

[c]Virally suppressed defined as having a viral load ≤200 copies per milliliter for most recent test in 2014

[d]Dependent areas are American Samoa, Guam, the Northern Mariana Islands, Puerto Rico, the Republic of Palau, and the U.S. Virgin Islands.

HIV = human immunodeficiency virus

CI = confidence interval

Ref. = reference group

three-drug highly active ART at treatment initiation. The low percentage of virally suppressed patients aged 20–29 years may also reflect challenges (e.g., choosing a new physician, communicating treatment histories) in the process of transitioning from pediatric to adult health care. Traditionally, pediatric and adolescent care sites offer a wider, more intensive range of psychosocial supports than adult care sites; studies have noted reduced rates of retention in care and viral suppression among patients transitioning to adult health care.[42–46] Our study found that patients aged 22 and 23 years had lower viral suppression proportions than those aged 21 years in New York City, where patients transition to adult care at age 21. However, because our study was cross-sectional, we could not make a conclusion based on our findings. A longitudinal analysis could monitor rates of retention in care and viral suppression among patients transitioning to adult care in New York City and determine the need for interventions.

Limitations

Our analysis had several limitations. First, we assumed that all people living with perinatally acquired HIV infection in New York City in 2014 had been diagnosed. A few patients in New York City may have acquired HIV perinatally outside of New York City and never received an HIV diagnosis or HIV care in New York City, but that number would be small. As such, our assumption of 100% diagnosis in this population is reasonable.

Second, because of the lack of ART information in the HIV registry, we were unable to include ART prescription as a component of the HIV care continuum. However, this exclusion did not affect the estimate of viral suppression, which is the ultimate goal in the HIV care continuum. Viral suppression was directly measured by using the viral load data in the registry independent of the previous step of ART prescription in the HIV care continuum. Given the natural history of HIV infection,[27] the wide availability of HIV treatment in New York City, and the recommendation of HIV treatment for all HIV-infected people regardless of their CD4 cell count,[17] the proportion of people with perinatally acquired HIV infection in New York City who are prescribed ART should be high. The low proportion of viral suppression in this population is likely a result of poor adherence to treatment and fewer current treatment options.

Third, we compared the study population—people living with perinatally acquired HIV infection—with all PLWH in New York City, but we did not compare them with young people who acquired HIV non-perinatally, because of some comparability issues: (*1*) the study population spanned ages 0–36 years and no one with non-perinatal transmission risk was younger than 14 years of age, and (*2*) PLWH with perinatal transmission risk had lived a lifetime with HIV infection, whereas young people with non-perinatal transmission risk had lived with HIV infection for only a few years.

CONCLUSION

We examined data on steps in the HIV care continuum among people living with perinatally acquired infection in NYC and identified the gaps in viral suppression. Although continuing support for adherence to treatment is needed, the data warrant further exploration to identify the best management strategies to improve viral suppression in this population, especially those transitioning from pediatric to adult health care.[42–49]

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