Survival Among New Yorkers with HIV from 1981 to 2017: Inequities by Race/Ethnicity and Transmission Risk Persist into the Post-HAART Era

Sarah L. Braunstein1,2,6 · Laura Kersanske1,3 · Lucia V. Torian1,2 · Rachael Lazar1,4 · Graham Harriman1,5

Accepted: 14 July 2021 / Published online: 18 September 2021
© The Author(s), under exclusive licence to Springer Science+Business Media, LLC, part of Springer Nature 2021

Abstract
Data on long-term survival among people with HIV (PWH) can inform the development of services for this population. An estimated 90,000 PWH live in New York City (NYC). Using HIV surveillance data, we conducted survival analysis of PWH diagnosed in NYC before and after introduction of highly active antiretroviral therapy (HAART) (pre-HAART cohort: 1981–1994; post-HAART cohort: 1995–2016). We created Kaplan–Meier curves by cohort and demographic factors, and Cox proportional hazards models to evaluate adjusted mortality risk by cohort. 205,584 adults and adolescents were diagnosed with HIV in NYC from 1981 to 2016, half each in the pre-HAART and post-HAART eras. The pre-HAART cohort had significantly poorer survival compared with the post-HAART cohort. Adjusted mortality risk in the pre-HAART cohort was almost threefold that in the post-HAART cohort (HR 2.84, 95% confidence interval [CI] 2.80–2.88). In sex- and risk-stratified models, men who have sex with men (MSM) had the largest difference in mortality risk pre-HAART versus post-HAART (HR 5.41, 95% CI 5.23–5.59). Race/ethnic disparities were pronounced among MSM, with Latino/Hispanic and White MSM having lower mortality than Black MSM. Females with heterosexual risk born outside the US had lower mortality than US-born women. The improvement in survival post-HAART was most pronounced for White people. Survival among persons diagnosed with HIV in NYC increased significantly since the introduction of HAART. However, among MSM and among PWH overall, improvements even post-HAART lagged for Black and Latino/Hispanic people, underscoring the need to address structural barriers, including racism, to achieve optimal health outcomes among people with HIV.

Keywords HIV · Antiretroviral therapy · Survival · Mortality · Risk factors

Introduction
New York City (NYC) has been an epicenter of the HIV epidemic in the United States since the early 1980s. The annual number of new AIDS diagnoses peaked in 1993, with 12,833 new diagnoses that year [1]. Deaths among New Yorkers with AIDS peaked in 1994 at 8334, the year before highly active antiretroviral therapy (HAART) was introduced [1]. The introduction and availability of HAART contributed directly to marked improvements in clinical outcomes for people living with HIV (PWH), and to sharp, positive changes in mortality rates among PWH and in general in the epidemiology of HIV in NYC and elsewhere [2–6].

NYC has a large and growing population of PWH, with an estimate of more than 90,000 people living with in NYC in 2018 [7]. With a steadily declining number of new HIV diagnoses and fewer deaths among PWH each year, an increasing proportion of PWH in NYC were diagnosed...
many years ago. There is growing interest in using epide-
miologic data to better quantify and describe long-term
survival among PWH in NYC. “Long-term survivors” can
include people who have lived with HIV for many years, or
those who were diagnosed in the era before HAART was
introduced and are still living today. Characterization of
long-term survival in the context of a long-established epi-
demic like NYC’s can shed light on population-level trends
in survival and mortality, identify differences in survival
across subpopulations of PWH, and underscore the role of
racism and other structural factors in driving and sustaining
inequities in survival among PWH over time.

In this analysis, we used population-based data from the
NYC HIV surveillance system to describe trends in long-
term survival among people diagnosed with HIV in NYC
from 1981 to 2016, before and after the introduction of
HAART, and to examine drivers of inequity in mortality
risk during this period.

Methods

Data Sources

Data on all HIV diagnoses from 1981 to 2016 were obtained
from the NYC Department of Health and Mental Hygiene’s
(DOHMH) HIV surveillance registry. The registry contains
information on all people diagnosed and reported with HIV
infection (since 2000) or AIDS (since 1981) in NYC. Pro-
viders are required to report all new diagnoses of HIV and
AIDS, and laboratories are required to report all positive
HIV diagnostic test algorithms, all qualitative and quantita-
tive viral load test results (including those that are undetect-
able), CD4 test results, and the nucleotide sequence gen-
erated during HIV genotypic resistance testing ordered by
NYC providers or for NYC residents. The registry receives
more than 1 million laboratory reports per year for people
living with diagnosed HIV and receiving HIV care in NYC.
Surveillance staff verify new HIV and AIDS diagnoses and
collect sociodemographic and clinical information through
medical chart review.

Information on deaths among PWH occurring in and out-
side NYC, including date of death, was obtained from rou-
tine matches of vital statistics data against the HIV registry.
Deaths among NYC PWH occurring in NYC are ascertained
via matches with the DOHMH’s vital statistics registry, and
deaths among NYC PWH that occur outside NYC are
ascertained through annual matches with the National Death
Index and Social Security Death Master File databases.

Data used for this analysis were collected as part of
legally mandated public health surveillance for HIV in New
York State; the analysis was therefore not subject to ethics
review.

Analytic Population

The analysis population consisted of all people aged ≥ 13
years at diagnosis and with an HIV diagnosis date
in the registry between January 1, 1981, and December 31,
2016. People known to have been diagnosed outside of NYC
were excluded from analysis (N = 9552), as were people with
a death date more than one month prior to their HIV diag-
nosis date (N = 68).

Exposure and Outcome Variables

The primary exposure variable was the individual person’s
diagnostic cohort. Diagnoses were initially categorized into
seven cohorts based on year of HIV diagnosis: 1981–1984,
1985–1989, 1990–1994, 1995–1999, 2000–2004,
2005–2009, and 2010–2016. Two distinct groupings were
seen in exploratory analyses of survival trends, with diver-
gent survival trends before and after 1995, the year that
HAART was introduced. Thus, for the primary analysis we
created two main diagnostic cohorts: a “pre-HAART cohort”
composed of people diagnosed with HIV from 1981 to 1994,
and a “post-HAART cohort” composed of people diagnosed
with HIV from 1995 to 2016.

The primary outcome of interest was death from any
cause. People in the analytic cohort were followed from date
of HIV diagnosis in 1/1/1981–12/31/2016 through the end
of the analytic period on 12/31/2017 or the date of death,
whichever occurred first.

Covariates

Sociodemographic and clinical variables included sex at
birth, age at diagnosis, race/ethnicity, HIV transmission risk,
county of residence at HIV diagnosis, country of origin, and
history of AIDS diagnosis. Sex at birth categories were male
or female. Age at diagnosis was categorized into approxi-
mately 10-year age groups, starting with 13–19 and ending
with 60+. Race/ethnicity categories followed standard clas-
sification by HIV surveillance, which classifies people iden-
tified as having Hispanic or Latino ethnicity as “Hispanic/
Latino” regardless of their racial identity, and all others
according to their racial identity. In this analysis, we limited
the race/ethnic categories to Black, Hispanic/Latino, White
and other or unknown race/ethnicity. The ‘HIV transmission
risk’ variable captured the presumed primary source of HIV
exposure prior to diagnosis, and categories followed stan-
dard surveillance classification: men who report sex with men
(MSM), history of injection drug use (IDU), heterosexual
contact, and other or unknown HIV transmission risk. NYC
county of residence and country of origin were based on
information available to surveillance at the time of a person’s HIV diagnosis. Finally, information on history of AIDS was based on an AIDS-defining CD4 cell count or diagnosis of an HIV-associated opportunistic infection reported to the surveillance registry.

Statistical Analysis

We described the sociodemographic characteristics of the analytic population, overall and by diagnostic cohort, and characterized PWH who died during the analytic period.

We generated Kaplan–Meier curves to describe survival trends by diagnostic cohort and by key demographic factors within diagnostic cohort, including sex at birth, race/ethnicity and HIV transmission risk. Log-rank tests were used to assess for statistically significant differences in survival by cohort and demographic factors, with p < 0.05 indicating statistical significance.

We used Cox Proportional Hazards models to estimate hazard ratios (HR) and 95% confidence intervals (CI) for the effect of sociodemographic factors on risk of death by diagnostic cohort. Potential confounders of the relationship between diagnostic cohort and death were explored first in bivariate, unadjusted models. Factors associated with death at p < 0.05 were analyzed in a multivariable model to predict death during the follow-up period. The proportional hazards assumption for each variable was assessed by analysis of residuals. Sex at birth, HIV transmission risk category, and race/ethnicity were each explored as potential effect modifiers of the relationship between diagnostic cohort and survival.

Results

A total of 205,584 adults and adolescents were newly diagnosed with HIV in NYC from 1981 to 2016, with 102,209 (49.7%) diagnosed in the pre-HAART era and 103,375 (50.3%) diagnosed in the post-HAART era. HIV diagnoses in NYC over the full period from 1981 to 2016 were more common among males (74.8%), those in their thirties at diagnosis (39.0%), Black people (43.2%), MSM (35.6%), people with history of IDU (31.7%), and Manhattan residents (25.0%) (Table 1). Similar demographics were seen by diagnostic cohort, although there were some differences by transmission risk and borough of residence at HIV diagnosis. In the pre-HAART cohort, diagnoses were most common among those with a history of IDU (47.1%). In the post-HAART cohort, diagnoses were most common among MSM (37.1%) and were equally common among Brooklyn (24.7%) and Manhattan (24.2%) residents. The proportion with a history of AIDS diagnosis differed by cohort, with 95.3% of pre-HAART PWH diagnosed with AIDS versus 60.6% of the post-HAART cohort; this is an artifact, in part, of the reporting law in effect between 1981 and 2000, during which time only AIDS diagnoses were reportable.

While 78,607 (76.9%) of those in the pre-HAART cohort had died by the end of 2017, only 26,303 (25.4%) of those in the post-HAART cohort had died by the end of 2017. The demographics of PWH in both the pre- and post-HAART cohorts who had died by the end of 2017 were similar to the demographics of people diagnosed with HIV in NYC from 1981 to 2016. Among the pre-HAART cohort, deaths were more common among males (78.6%), those diagnosed in their thirties (45.7%), Black people (38.8%), those with a history of IDU (50.8%), and Manhattan residents (26.5%). Among the post-HAART cohort, deaths were more common among males (69.1%), those diagnosed in their forties (34.4%), Black people (55.2%), those with a history of IDU (34.2%), and Brooklyn residents (26.0%).

Survival curves show a difference in survival after diagnosis for the pre-HAART cohort as compared to the post-HAART cohort (Fig. 1). The pre-HAART cohort experienced a rapid decline in survival within the first 5 years after HIV diagnosis, followed by a more gradual decline. The post-HAART cohort had significantly better survival compared with the pre-HAART cohort (p < 0.05) and did not experience the same drop in survival in the early years after diagnosis, presumably because most patients with advanced disease received HAART immediately after diagnosis. Survival curves stratified by demographic characteristics and cohort explored differences in survival by sex at birth, age, race/ethnicity, and transmission risk (Fig. 2). The sex-stratified curves showed a significant difference in survival (p < 0.05) between males and females for the pre-HAART cohort, although this difference was no longer present in the post-HAART cohort, and survival improved for both males and females. The race/ethnicity-stratified curves showed disparities in survival by race/ethnicity for both cohorts (p < 0.05). Poorest survival was seen among White people in the pre-HAART cohort but among Black and Latino/Hispanic people in the post-HAART cohort. For the transmission risk-stratified curves, disparities in survival by transmission risk category were seen for both cohorts (p < 0.05). MSM had among the poorest survival in the pre-HAART cohort, but highest in the post-HAART cohort; people with a history of IDU in both cohorts had and continued to have the worst long-term survival of the four major transmission risk groups. These characteristics were explored further with Cox proportional hazards models.

Sex at birth, age at HIV diagnosis, race/ethnicity, transmission risk, country of origin, and history of AIDS diagnosis at the time of diagnosis were found to be confounders of the association between diagnostic cohort and mortality risk; all were included in the final multivariable model. County of residence at HIV diagnosis was also found to be significant.
Table 1  Demographic and clinical characteristics of people diagnosed with HIV from January 1, 1981 through December 31, 2016 in New York City, by vital status in 2017 and diagnostic cohort

| Total | 1981–1994, Pre-HAART cohort | 1995–2016, Post-HAART cohort |
|-------|-----------------------------|-----------------------------|
|       | Total (N (%) = 205,584)     | Total (N (%) = 103,375)     |
|       | Alive (N (Col %) = 102,209) | Alive (N (Col %) = 77,072) |
|       | Not alive (N (Col %) = 23,602) | Not alive (N (Col %) = 78,607) |

**Vital status as of 12/31/2017**

| Total | 1981–1994, Pre-HAART cohort | 1995–2016, Post-HAART cohort |
|-------|-----------------------------|-----------------------------|
|       | Total (N (%) = 205,584)     | Total (N (%) = 103,375)     |
|       | Alive (N (Col %) = 102,209) | Alive (N (Col %) = 77,072) |
|       | Not alive (N (Col %) = 23,602) | Not alive (N (Col %) = 78,607) |

**Sex at birth**

|     | Total | 1981–1994, Pre-HAART cohort | 1995–2016, Post-HAART cohort |
|-----|-------|-----------------------------|-----------------------------|
|     | Total (N (%) = 205,584)     | Total (N (%) = 103,375)     |
|     | Alive (N (Col %) = 102,209) | Alive (N (Col %) = 77,072) |
|     | Not alive (N (Col %) = 23,602) | Not alive (N (Col %) = 78,607) |

**Age at HIV diagnosis**

|     | 13–19 | 20–29 | 30–39 | 40–49 | 50–59 | 60+ |
|-----|-------|-------|-------|-------|-------|-----|
|     | Total (N (%) = 205,584)     | Total (N (%) = 103,375)     |
|     | Alive (N (Col %) = 102,209) | Alive (N (Col %) = 77,072) |
|     | Not alive (N (Col %) = 23,602) | Not alive (N (Col %) = 78,607) |

**Race/ethnicity**

|     | Black | Latino/Hispanic | White | Other/Unknown |
|-----|-------|-----------------|-------|--------------|
|     | Total (N (%) = 205,584)     | Total (N (%) = 103,375)     |
|     | Alive (N (Col %) = 102,209) | Alive (N (Col %) = 77,072) |
|     | Not alive (N (Col %) = 23,602) | Not alive (N (Col %) = 78,607) |

**Transmission risk**

|     | Men who have sex with men | Injection drug use history | Heterosexual contact | Other/unknown | Total (N (%) = 205,584)     | Total (N (%) = 103,375)     |
|-----|---------------------------|---------------------------|---------------------|--------------|-----------------------------|-----------------------------|
|     | Total (N (%) = 205,584)   | Total (N (%) = 103,375)   |
|     | Alive (N (Col %) = 102,209) | Alive (N (Col %) = 77,072) |
|     | Not alive (N (Col %) = 23,602) | Not alive (N (Col %) = 78,607) |

**Borough at HIV diagnosis**

|     | Bronx | Brooklyn | Manhattan |
|-----|-------|----------|-----------|
|     | Total (N (%) = 205,584)     | Total (N (%) = 103,375)     |
|     | Alive (N (Col %) = 102,209) | Alive (N (Col %) = 77,072) |
|     | Not alive (N (Col %) = 23,602) | Not alive (N (Col %) = 78,607) |
in the bivariate model but was excluded from the final multivariable model due to its violation of the proportionality assumption. In the adjusted Cox proportional hazards model, people in the pre-HAART diagnostic cohort had almost 3 times higher mortality risk as compared to those in the post-HAART diagnostic cohort (AHR 2.84, 95% CI 2.80–2.88). In general during the analytic period, PWH with a history of IDU had a higher mortality risk than MSM (AHR 1.24, 95% CI 1.22–1.26) (Table 2).

Sex, transmission risk category, and race/ethnicity were found to be potential effect modifiers of the relationship between diagnostic cohort and mortality risk. These interactions were explored further in stratified multivariable analyses. In sex- and risk-stratified models (Table 2), the largest difference in mortality risk for the pre-HAART versus post-HAART cohort was seen among MSM. After controlling for demographic and clinical characteristics, MSM in the pre-HAART cohort had a mortality risk over 5 times higher than the risk of MSM in the post-HAART cohort (AHR 5.41, 95% CI 5.23–5.59). Significant differences in mortality risk by cohort were also seen among males with a history of IDU (AHR 1.98, 95% CI 1.93–2.04), male heterosexuals (AHR 2.03, 95% CI 1.87–2.20), females with a history of IDU (AHR 2.01, 95% CI 1.92–2.11), and female heterosexuals (AHR 3.00, 95% CI 2.87–3.14). Older age at diagnosis and a history of AIDS diagnosis (versus HIV only) were significantly associated with higher mortality risk in the overall model and for all sex/risk subgroups. PWH in the 40–49, 50–59, and 60+ age groups at HIV diagnosis had 1.29, 1.77, and 2.60 times higher mortality risk, respectively, compared to those diagnosed at ages 30–39. Male heterosexuals...
diagnosed at age 60+ had a particularly high mortality risk compared to male heterosexuals diagnosed at ages 30–39 (AHR 4.25, 95% CI 3.69–4.88). PWH without a history of AIDS diagnosis (HIV only) had a much lower risk of mortality compared to those ever diagnosed with AIDS (AHR 0.21, 95% CI 0.21–0.22); this association held among all sex/risk subgroups. While Latino/Hispanic PWH had lower mortality compared to Black PWH in all models, race/ethnic disparities were particularly pronounced among MSM. Both Latino/Hispanic MSM (AHR 0.82, 95% CI 0.79–0.85) and White MSM (AHR 0.91, 95% CI 0.88–0.93) had lower mortality risk compared to Black MSM. The only significant association between country of origin and mortality risk was seen among heterosexual females: those born outside the US had lower mortality than those born in the US or with an unknown country of birth (AHR 0.78, 95% CI 0.73–0.83).

In the race/ethnicity-stratified model, survival improved significantly for all race/ethnic groups from the pre-HAART cohort to the post-HAART cohort (Table 3). However, the most dramatic improvement was seen among White PWH, with a nearly four-fold higher mortality risk in the pre-HAART cohort compared with the post-HAART cohort (AHR 3.95, 95% CI 3.80–4.11).

Discussion

Examination of long-term survival among NYC PWH over a nearly 40-year period revealed marked improvements in survival among both men and women, all races/ethnicities, and all transmission risk groups after the introduction of HAART. Only approximately one-quarter of people diagnosed with HIV before 1995 were still living by 2017, as compared with approximately three-quarters of those diagnosed with HIV from 1995 to 2016. In both the pre- and post-HAART eras, people newly diagnosed with HIV and those with HIV who died were mostly men, people in their
Table 2  Mortality risk of people diagnosed with HIV from January 1, 1981 through December 31, 2016 in New York City, by sex at birth and HIV transmission risk category

|                              | Overall                        | Men who have sex with men | Male, injection drug use history | Male, heterosexual | Female, injection drug use history | Female, heterosexual |
|------------------------------|--------------------------------|---------------------------|---------------------------------|-------------------|-----------------------------------|----------------------|
|                              | AHR (95% CI)                   | AHR (95% CI)              | AHR (95% CI)                    | AHR (95% CI)      | AHR (95% CI)                      | AHR (95% CI)         |
| Diagnostic cohort            |                                |                           |                                 |                   |                                   |                      |
| 1981–1994, Pre-HAART         | 2.84 (2.80, 2.88)              | 5.41 (5.23, 5.59)         | 1.98 (1.93, 2.04)               | 2.03 (1.87, 2.20) | 2.01 (1.92, 2.11)                 | 3.00 (2.87, 3.14)    |
| 1995–2016, Post-HAART        | (Ref)                          | (Ref)                     | (Ref)                           | (Ref)             | (Ref)                             | (Ref)                |
| Sex at birth                 |                                |                           |                                 |                   |                                   |                      |
| Male                         | (Ref)                          |                           | n/a                             | n/a               | n/a                               | n/a                  |
| Female                       | 1.03 (1.01, 1.04)              |                           | n/a                             | n/a               | n/a                               | n/a                  |
| Age at HIV diagnosis         |                                |                           |                                 |                   |                                   |                      |
| 13–19                        | 0.36 (0.33, 0.38)              | 0.34 (0.30, 0.38)         | 0.27 (0.23, 0.33)               | 0.37 (0.24, 0.59) | 0.34 (0.28, 0.43)                 | 0.42 (0.36, 0.49)    |
| 20–29                        | 0.64 (0.63, 0.65)              | 0.62 (0.60, 0.64)         | 0.62 (0.60, 0.64)               | 0.69 (0.61, 0.78) | 0.68 (0.65, 0.72)                 | 0.71 (0.67, 0.75)    |
| 30–39                        | (Ref)                          | (Ref)                     | (Ref)                           | (Ref)             | (Ref)                             | (Ref)                |
| 40–49                        | 1.29 (1.27, 1.31)              | 1.29 (1.25, 1.33)         | 1.21 (1.18, 1.24)               | 1.46 (1.33, 1.61) | 1.20 (1.14, 1.25)                 | 1.30 (1.23, 1.37)    |
| 50–59                        | 1.77 (1.73, 1.81)              | 1.76 (1.69, 1.83)         | 1.49 (1.43, 1.55)               | 2.25 (2.01, 2.52) | 1.49 (1.37, 1.62)                 | 1.74 (1.61, 1.87)    |
| 60+                          | 2.69 (2.60, 2.78)              | 2.36 (2.22, 2.52)         | 1.86 (1.72, 2.01)               | 4.25 (3.69, 4.88) | 2.23 (1.86, 2.67)                 | 2.71 (2.44, 3.00)    |
| Race/ethnicity               |                                |                           |                                 |                   |                                   |                      |
| Black                        | (Ref)                          | (Ref)                     | (Ref)                           | (Ref)             | (Ref)                             | (Ref)                |
| Latino/Hispanic              | 0.90 (0.88, 0.91)              | 0.82 (0.79, 0.85)         | 0.93 (0.91, 0.95)               | 0.92 (0.85, 1.00) | 0.88 (0.85, 0.92)                 | 0.91 (0.87, 0.95)    |
| White                        | 1.02 (1.00, 1.03)              | 0.91 (0.88, 0.93)         | 1.06 (1.03, 1.10)               | 0.99 (0.86, 1.13) | 0.99 (0.94, 1.05)                 | 0.98 (0.91, 1.06)    |
| Other/unknown                | 0.76 (0.71, 0.81)              | 0.68 (0.61, 0.75)         | 0.80 (0.68, 0.95)               | 0.75 (0.57, 0.97) | 0.79 (0.56, 1.12)                 | 0.76 (0.61, 0.96)    |
| Transmission risk            |                                |                           |                                 |                   |                                   |                      |
| Men who have sex with men    | (Ref)                          | n/a                       | n/a                             | n/a               | n/a                               | n/a                  |
| Injection drug use history   | 1.24 (1.22, 1.26)              | n/a                       | n/a                             | n/a               | n/a                               | n/a                  |
| Heterosexual contact         | 0.79 (0.77, 0.81)              | n/a                       | n/a                             | n/a               | n/a                               | n/a                  |
| Other/unknown                | 0.88 (0.86, 0.90)              | n/a                       | n/a                             | n/a               | n/a                               | n/a                  |
| Country of origin            |                                |                           |                                 |                   |                                   |                      |
| US-born/unknown              | (Ref)                          | (Ref)                     | (Ref)                           | (Ref)             | (Ref)                             | (Ref)                |
| Born outside US              | 0.99 (0.97, 1.01)              | 1.03 (1.00, 1.06)         | 0.97 (0.93, 1.02)               | 0.96 (0.88, 1.05) | 0.93 (0.85, 1.03)                 | 0.78 (0.73, 0.83)    |
| History of AIDS diagnosis    |                                |                           |                                 |                   |                                   |                      |
| No AIDS diagnosis (HIV only) | 0.21 (0.21, 0.22)              | 0.14 (0.13, 0.15)         | 0.31 (0.29, 0.33)               | 0.31 (0.27, 0.36) | 0.30 (0.27, 0.33)                 | 0.20 (0.18, 0.22)    |
| AIDS diagnosis               | (Ref)                          | (Ref)                     | (Ref)                           | (Ref)             | (Ref)                             | (Ref)                |

*AHR* adjusted hazard ratio, *CI* confidence interval, *HAART* highly active antiretroviral therapy, *US* United States
30 s, Black people, and people with a history of IDU or MSM.

Despite overall improvements in survival, we identified inequities in survival across different groups even after the introduction of HAART, with inequities widening over time. Gains in survival in the post-HAART era were steepest for White people and for MSM, and among MSM, White MSM had the lowest mortality risk. These findings mirror data on the HIV epidemic in NYC more broadly, with Black and Latino/Hispanic people bearing the heaviest burden of HIV and generally experiencing poorer HIV outcomes than White people [7]. Additionally, our observation of poorest survival among White people in the pre-HAART cohort and among Black and Latino/Hispanic people in the post-HAART cohort, despite the availability of effective treatment, underscores structural barriers and racism as essential issues affecting health outcomes in the post-HAART era. In both eras, people with a history of IDU had the poorest survival. This reflects, among other factors, the older age distribution among newly diagnosed IDU compared with those of other transmission risk groups [1], as well as the high prevalence of co-morbidities among this group of PWH [8].

NYC has an important history as a center of HIV activism and HIV-related scientific and policy innovation. NYC is the birthplace of central HIV advocacy institutions including AIDS Coalition to Unleash Power (ACT UP), Treatment Action Group (TAG), The National Gay Men’s Health Crisis (GMHC) and the National Black Leadership Commission on AIDS (NBLCA). HIV activism remains strong and effective in NYC, supporting and contributing to a statewide plan to End the Epidemic [9] and advocating for increased services to address the needs of long-term survivors. Local efforts to address the needs of and improve outcomes for long-term survivors have been made in coordination with a national effort to meet the needs of an aging population of PWH.

DOHMH’s Bureau of HIV first produced survival curves for pre- and post-HAART cohorts in response to a request from ACT UP NY for Long Term Survivors’ Awareness Day on June 5, 2015. These data proved to be a powerful tool to communicate the disproportionate impact of mortality on

---

**Table 3** Mortality risk of people diagnosed with HIV from January 1, 1981 through December 31, 2016 in New York City, by race/ethnicity

|                          | Black PWH | Latino/Hispanic PWH | White PWH | PWH with other/unknown race/ethnicity |
|--------------------------|-----------|---------------------|-----------|--------------------------------------|
|                          | AHR 95% CI| AHR (95% CI)        | AHR (95% CI) | AHR (95% CI)                        |
| Diagnostic cohort        |           |                     |           |                                      |
| 1981–1994, Pre-HAART     | 2.49 2.44, 2.55 | 2.80 2.73, 2.88 | 3.95 3.80, 4.11 | 3.52 3.07, 4.05                    |
| 1995–2016, Post-HAART     | (Ref) –    | (Ref) –             | (Ref) –   | (Ref) –                             |
| Sex at birth             |           |                     |           |                                      |
| Male                     | (Ref) –    | (Ref) –             | (Ref) –   | (Ref) –                             |
| Female                   | 1.04 1.01, 1.06 | 1.02 0.99, 1.04 | 0.99 0.94, 1.03 | 1.06 0.86, 1.30                    |
| Age at HIV diagnosis     |           |                     |           |                                      |
| 13–19                    | 0.35 0.32, 0.39 | 0.34 0.30, 0.38 | 0.38 0.32, 0.46 | 0.49 0.23, 1.04                     |
| 20–29                    | 0.64 0.62, 0.66 | 0.65 0.64, 0.67 | 0.62 0.60, 0.65 | 0.73 0.59, 0.90                     |
| 30–39                    | (ref) –    | (ref) –             | (ref) –   | (ref) –                             |
| 40–49                    | 1.26 1.23, 1.29 | 1.31 1.28, 1.35 | 1.30 1.26, 1.34 | 1.67 1.43, 1.95                     |
| 50–59                    | 1.75 1.70, 1.81 | 1.77 1.70, 1.84 | 1.75 1.68, 1.83 | 2.26 1.85, 2.77                     |
| 60+                      | 2.59 2.47, 2.71 | 2.92 2.74, 3.11 | 2.51 2.34, 2.69 | 4.56 3.45, 6.02                     |
| Transmission risk        |           |                     |           |                                      |
| Men who have sex with men| (Ref) –    | (Ref) –             | (Ref) –   | (Ref) –                             |
| Injection drug use history| 1.21 1.18, 1.24 | 1.36 1.32, 1.41 | 1.20 1.17, 1.25 | 1.72 1.42, 2.08                     |
| Heterosexual contact     | 0.74 0.72, 0.77 | 0.85 0.82, 0.89 | 0.84 0.78, 0.90 | 0.83 0.66, 1.04                     |
| Other/unknown            | 0.85 0.82, 0.88 | 0.91 0.88, 0.95 | 0.86 0.82, 0.90 | 1.15 0.97, 1.35                     |
| Country of origin        |           |                     |           |                                      |
| US-born/unknown          | (Ref) –    | (Ref) –             | (Ref) –   | (Ref) –                             |
| Born outside US          | 0.93 0.90, 0.95 | 1.05 1.02, 1.08 | 0.98 0.93, 1.02 | 1.67 1.45, 1.92                     |
| History of AIDS diagnosis|           |                     |           |                                      |
| No AIDS diagnosis (HIV only) | 0.24 0.23, 0.25 | 0.23 0.22, 0.24 | 0.16 0.15, 0.18 | 0.20 1.16, 0.26                     |
| AIDS diagnosis           | (Ref) –    | (Ref) –             | (Ref) –   | (Ref) –                             |
long-term survivors, which then led to important discussion at the meeting and the generation of data-informed ideas for improving services and programming for long-term survivors and aging PWH in NYC.

Pre-HAART and post-HAART survival data validate the challenges experienced by these populations. For pre-HAART PWH, these data provide context for individuals’ and communities’ stories of survival and recognition of the impact of the loss of their peers, with three-quarters of this population no longer living. For post-HAART PWH, findings can be used to strengthen the healthcare environment for PWH so that clinical and other outcomes, including survival, improve uniformly across race/ethnicity, gender, risk factor, and geography. These data can inform advocacy for increased focus on health equity and specifically to support and strengthen ongoing efforts to reduce HIV-related burden and improve outcomes for Black and Latino/Hispanic PWH in NYC. The DOHMH Bureau of Hepatitis, HIV, and Sexually Transmitted Infections (BHHS) has multiple programs that address the disproportionate impact of HIV on Black and Latino people, including long-term survivors. For example, Project THRIVE works to improve coordination and provision of HIV prevention and care services to Black and Latino MSM in Brooklyn, offering lab-based HIV testing in nonclinical settings, integrating STI screening in community settings, referring and navigating clients to PrEP and PEP services, and referring and linking clients to HIV care and behavioral health and support services. Service providers and agencies within BHHS’ PlaySure Network identify Black and Latino people and MSM, including Black and Latino MSM, as priority populations for services including HIV and STI testing, PrEP and PEP, and HIV care and support services. Finally, BHHS recently engaged in a community-driven planning process to expand and enhance NYC’s plan to end the HIV epidemic. The new plan employs a health-equity lens and names specific priority populations for programming and policy work, including Black and Latino people, MSM of color and older PWH.

This analysis has multiple strengths. Chief among them is the use of population-level data that enabled analysis of mortality trends over a period of nearly 40 years. The surveillance dataset is comprehensive, standardized, and large. We were able to identify associations between key sociodemographic characteristics and survival among New Yorkers with HIV; to our knowledge, this is the first analysis of its kind in a US jurisdiction. The findings of our analysis have important implications for current work by DOHMH to reduce inequities in the distribution and outcomes of HIV in NYC.

The analysis also has limitations. First, because HIV diagnostic testing was not available early in the epidemic and mandatory reporting of HIV infection was only implemented in the year 2000, there could be inaccuracies in HIV diagnosis date, particularly for people in the pre-HAART cohort, leading to possible differential misclassification of cohort membership. In addition, some surveillance data collection practices have changed over time, as has the availability of data for collection by the surveillance program, and these changes have potential consequences for this analysis. For example, changes in ascertainment of patient sexual history and drug-use behavior by providers over time could influence (either positively or negatively) the accuracy of transmission risk classification by surveillance as well as the completeness of these data. In this analysis, the proportion of individuals with unknown transmission risk was substantially higher in the post-HAART cohort compared to the pre-HAART cohort, likely due to changes over this period from most pre-HAART HIV diagnoses being made in inpatient settings where there was more opportunity for patient interview and data collection, to post-HAART diagnoses being made largely in outpatient settings where in-depth data collection is more difficult. In addition, DOHMH began interviewing individuals with new HIV diagnoses for partner services purposes in 2006, which added a new (and improved) source of information on patient characteristics such as race/ethnicity and HIV exposure history. Other data limitations exist. For example, although surveillance now captures information on current gender identity of people living with diagnosed HIV and reported to the surveillance registry, those data were not available for the full analytic period and so could not be incorporated into our analysis. In addition, information on treatment initiation or status are not collected by surveillance, which prevented us from examining mortality risk by use of HAART; we only have ecological data on HAART, not individual-level use. Finally, and importantly, although surveillance data powerfully describe trends at the population-level, they lack the depth to shed light on the many important factors underlying and driving some of our findings related to long-term survival with HIV. These factors include resilience, the role of social and other support, mental health, substance use (beyond surveillance information on history of IDU), housing, income, access to care and service utilization, and quality of care, among others. Future analyses can also explore the role of HIV as a cause of death among PWH.

Conclusion

As NYC works to end its HIV epidemic, the opportunity to learn from the past and to use available information to identify persistent inequities is more critical than ever. Development and implementation of programs and services for populations at higher risk of mortality even in the era of HAART will be a continued priority, as will
focused work with long-term survivors to address mental health needs, reduce social isolation, and prevent and treat comorbidities.

Acknowledgements We acknowledge staff in the HIV Epidemiology Program of the New York City Department of Health and Mental Hygiene for their important contributions to the HIV Surveillance Registry, the data source for this analysis, as well as all staff in the Bureau of Hepatitis, HIV, and Sexually Transmitted Infections for their many contributions to ending the HIV epidemic in NYC over the last four decades. We also acknowledge the HIV activist community and other community partners in NYC for their tireless efforts. Finally, we acknowledge all New Yorkers living with and affected by HIV, especially the long-term survivors.

Author Contributions SLB, LK, LVT and GH conceived of and designed the analysis. LK and RL conducted the analyses. SLB, LK, LVT, RL and GH wrote the manuscript.

Funding This work was supported by the Centers for Disease Control and Prevention [1 U62PS924575-01-00].

Declarations

Conflict of interest The authors have no conflicts of interest to declare.

Ethical approval Data used for this analysis were collected as part of legally mandated public health surveillance for HIV in New York State; the analysis was therefore not subject to ethics review.

References

1. HIV Epidemiology Program. NYC HIV/AIDS Annual Surveillance Statistics 2018. New York City Department of Health and Mental Hygiene: New York, NY. https://www1.nyc.gov/assets/doh/downloads/pdf/ah/surveillance-trend-tables.pdf. Accessed 14 Oct 2020.
2. Chiasson MA, Berenson L, Li W, Schwartz S, Singh T, Mojica BA, et al. Declining HIV/AIDS mortality in New York City. J Acquir Immune Defic Syndr. 1999;21(1):59–64.
3. Chiasson MA. Declining AIDS mortality in New York City. New York City Department of Health. Bull NY Acad Med. 1997;74(1):151–2.
4. Wong T, Chiasson MA, Reggy A, Simonds RJ, Heffness J, Loo V. Antiretroviral therapy and declining AIDS mortality in New York City. J Urban Health. 2000;77(3):492–500.
5. Chiasson MA. New York City AIDS case mortality rates in the era of potent antiretroviral therapy. J Urban Health. 2000;77(2):255–7.
6. Altman LK. Deaths from AIDS decline sharply in New York City. The New York Times. 1997 January 25; section 1, page 1.
7. HIV Epidemiology Program. HIV Surveillance Annual Report, 2018. New York City Department of Health and Mental Hygiene: New York, NY. November 2019.
8. Kamarulzaman A, Altice FL. Challenges in managing HIV in people who use drugs. Curr Opin Infect Dis. 2015;28(1):10–6.
9. Ending the Epidemic Blueprint, 2015. New York State Department of Health: New York, US. https://www.health.ny.gov/diseases/aids/ending_the_epidemic/docs/blueprint.pdf. Accessed 14 Oct 2020.

Publisher’s Note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.