

# Human Immunodeficiency Virus Infection Newly Diagnosed at Autopsy in New York City, 2008–2012

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**Background.** Studying the most extreme example of late diagnosis, new HIV diagnoses after death, may be instructive to HIV testing efforts. Using the results of routine HIV testing of autopsies performed by the Office of Chief Medical Examiner (OCME), we identified new HIV diagnoses after death in New York City (NYC) from 2008 to 2012.

**Methods.** Population-based registries for HIV and deaths were linked to identify decedents not known to be HIV-infected before death. Multivariable logistic regression models were constructed to determine correlates of a new HIV diagnosis after death among all persons newly diagnosed with HIV and among all HIV-infected decedents receiving an OCME autopsy.

**Results.** Of 264 893 deaths, 24 426 (9.2%) were autopsied by the NYC OCME. Of these, 1623 (6.6%) were infected with HIV, including 142 (8.8%) with a new HIV diagnosis at autopsy. This represents 0.8% (142 of 18 542) of all new HIV diagnoses during the 5-year period. Decedents newly diagnosed with HIV at OCME autopsy were predominantly male (73.9%), aged 13–64 years (85.9%), non-white (85.2%), unmarried (81.7%), less than college educated (83.8%), and residents of an impoverished neighborhood (62.0%). Of all HIV-infected OCME decedents aged  $\geq 65$  years ( $n = 71$ ), 22.0% were diagnosed at autopsy. The strongest independent correlate of new HIV diagnosis at autopsy in both multivariable models was age  $\geq 65$  years.

**Conclusions.** Human immunodeficiency virus diagnoses first made after death are rare, but, when observed, these diagnoses are more commonly found among persons  $\geq 65$  years, suggesting that despite highly visible efforts to promote HIV testing community-wide, timely diagnosis among older adults living in impoverished, high-prevalence neighborhoods may require additional strategies.

**Keywords.** autopsy; HIV diagnoses at autopsy; HIV diagnosis at death; new HIV diagnoses.

Human immunodeficiency virus (HIV) antibody testing became available in the United States in 1985 and was quickly deployed in HIV seroprevalence studies of selected populations to improve the medical and

public health communities' nascent understanding of HIV epidemiology [1, 2]. Along with studies of populations of military recruits [1], blood donors [1], pregnant women at antenatal clinics, and other sentinel populations [1], HIV serosurveys among all autopsied persons in a defined geographic area and period of time have yielded important epidemiologic findings [3–5]. In New York City (NYC), the first autopsy seroprevalence studies published in the early 1990s demonstrated the disproportionate burden of HIV among men, blacks, Hispanics, and persons in their 30s and 40s [4, 5]—all features of NYC's HIV epidemiology that remain true to the present time [6].

Almost 25 years after the initial autopsy seroprevalence studies in NYC were performed, HIV screening of all autopsied persons has remained the standard

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practice of the NYC Office of the Chief Medical Examiner (OCME). However, many other new means of identifying the distribution and determinants of HIV have also become available [7, 8]. Human immunodeficiency virus reporting by name to the New York State (NYS) Department of Health (DOH) was made law in 2000, with comprehensive cluster of differentiation 4 (CD4) on lymphocyte and viral load test result reporting by laboratories made mandatory a few years later (2005) [9].

In addition, NYC and NYS have been at the forefront of a major national push to make HIV testing a routine part of clinical care to assure prompt linkage to care and treatment to improve clinical outcomes and avert the increased morbidity and mortality associated with late diagnosis.

The NYC DOH and Mental Hygiene (DOHMH) introduced rapid HIV testing in sexually transmitted disease clinics city-wide in 2004 [10], and a few years later they adopted an opt-out testing model for all clients. The DOHMH instituted rapid HIV testing in city correctional facilities [11] and steadily expanded HIV partner notification and contact tracing services, reaching citywide coverage by the end of 2012 [12]. These efforts resulted in steady year-after-year increases for a decade so that by 2012, nearly two thirds of NYC adults reported having been tested for HIV at least once during their lifetime [13].

For several years, the city has closely tracked its progress in reducing late diagnosis by following the proportion of acquired immune deficiency syndrome (AIDS) diagnoses made within 1 month of an HIV diagnosis, also called “concurrent diagnoses” [14]. This proportion has decreased in recent years, suggesting broader testing of appropriate populations.

However, cases continue to be first diagnosed at autopsy. This group presumably represents the most extreme example of late HIV diagnosis, and it may therefore be particularly instructive to inform HIV testing efforts aimed at timely diagnosis.

To examine trends in persons first diagnosed with HIV at autopsy, we linked HIV surveillance data and death certificate data from 2008 to 2012. We compared this group to (1) all other persons newly diagnosed with HIV in NYC during this time and (2) all other OCME-autopsied decedents testing HIV positive, to establish factors associated with HIV diagnosis after death.

## METHODS

### Data Sources and Study Population

The NYC HIV Surveillance Registry (HSR) is a population-based registry of all persons in NYC diagnosed with AIDS since 1983 and with HIV since 2000. By law, these diagnoses are reported to the NYC DOHMH via NYS DOH. Most reports of new diagnoses are first received as part of mandatory HIV-related laboratory reporting, which, since 2005, has included all positive Western blot results, all CD4 cell counts, all HIV viral load values, and all HIV nucleotide sequencing results.

Approximately half of all cases are also reported to NYC DOHMH by clinical providers. All incoming reports are matched to the HSR.

Any nonmatching report representing a potentially previously unreported diagnosis of HIV in NYC is investigated by the Bureau of HIV/AIDS Prevention and Control (BHIV) field surveillance staff through a medical record review at the ordering facility. By reviewing medical records, field surveillance personnel (1) confirm that the case meets standard surveillance case definitions [7–9, 15] and (2) supplement laboratory data with sociodemographic and clinical information.

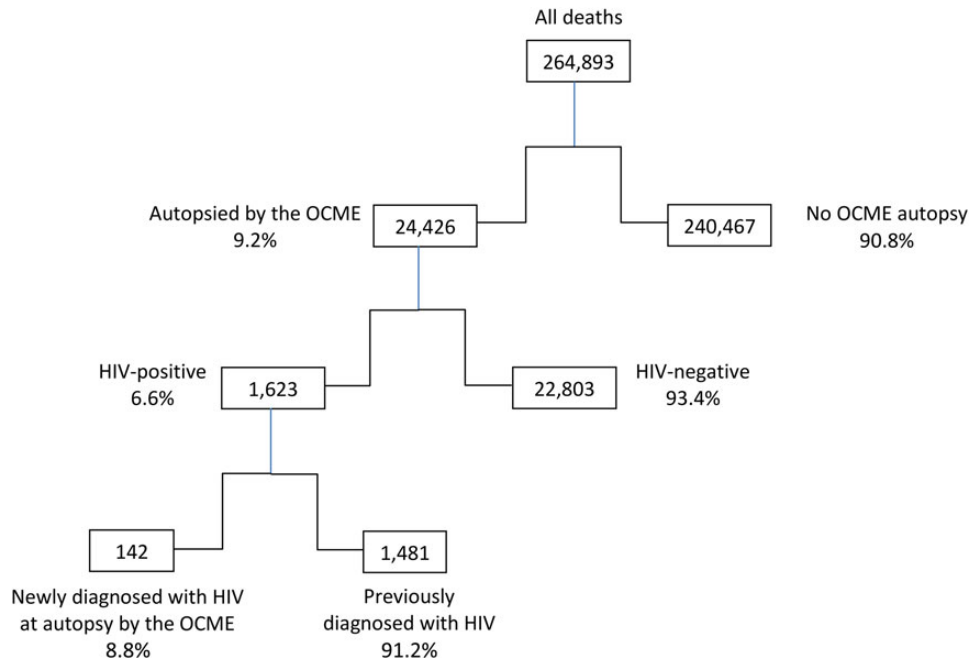
Deaths among HIV cases in the HSR are ascertained through quarterly linkages with NYC death certificate data maintained in the NYC Vital Statistics Registry (VSR). Deaths occurring outside NYC are ascertained by annual record linkages with the National Death Index and the Social Security Death Master File [15].

The VSR includes all data reported to the DOHMH on death certificates for deaths occurring in NYC. These data include decedent sociodemographics and the specific location and manner of death. The VSR also includes the cause of death, whether an autopsy was performed, and, if so, whether that autopsy was performed by the NYC OCME. Decedents undergoing autopsy by the OCME are assigned causes of death using autopsy findings, which are entered on death certificates submitted to the VSR.

The NYC OCME investigates cases of persons who die within NYC as a result of criminal violence, accident, suicide, suddenly when in apparent health, when unattended by a physician, in a correctional facility, in any suspicious or unusual manner, or where an application is made pursuant to law for a permit to cremate a decedent’s body [4, 5, 16]. All OCME-autopsied decedents had HIV diagnostic testing performed by the NYC DOHMH Public Health Laboratory, which used a standard algorithm that combined a third-generation enzyme immunoassay followed by a confirmatory Western blot [17]. Human immunodeficiency virus testing results are provided to OCME clinical staff, and those autopsied decedents determined to be infected with HIV are reported to BHIV in accordance with NYS’s legal mandate for provider reporting of cases of HIV.

All HIV case reports originating from the OCME prompt an onsite medical record review by a BHIV public health advisor specifically assigned to the OCME. This medical record review is conducted to supplement existing information if the case is found to be previously reported or to obtain new information necessary for surveillance if the case is new to the HSR.

The study populations included all persons who were newly diagnosed with HIV in NYC from January 1, 2008 through December 31, 2012 and reported to the HSR, as well as all reported deaths in NYC from January 1, 2008 through December 31, 2012. The particular focus of this analysis was that subset of the study population who were newly diagnosed with HIV infection as a result of HIV testing at NYC OCME autopsy.



**Figure 1.** All deaths in New York City, 2008–2012. Abbreviations: HIV, human immunodeficiency virus; OCME, Office of Chief Medical Examiner.

**Table 1. Newly Diagnosed HIV Infection at OCME Autopsy Among All Newly Diagnosed Persons 13 Years and Older in NYC, 2008–2012**

	All New HIV Infections		Newly Diagnosed HIV Infection							AOR (95% CI)	P Value
			At OCME Autopsy			During Life					
	N	%	N	Column %	Row %	N	Column %	Row %			
Total	18 542	100	142	100	0.77	18 400	100	99.23	—	—	
Sex											
Male	14 443	77.89	105	73.94	0.73	14 338	77.92	99.27	0.96 (.65–1.42)	.84	
Female	4099	22.11	37	26.06	0.9	4062	22.08	99.1	Ref	Ref	
Age											
13–64	18 152	97.9	122	85.92	0.67	18 030	97.99	99.33	Ref	Ref	
≥65	<b>390</b>	<b>2.1</b>	<b>20</b>	<b>14.08</b>	<b>5.13</b>	<b>370</b>	<b>2.01</b>	<b>94.87</b>	<b>7.67 (4.70–12.51)</b>	<b>&lt;.0001</b>	
Race/ethnicity											
Black, non-Hispanic	8664	46.73	74	52.11	0.85	8590	46.68	99.15	1.30 (.74–2.28)	.37	
Hispanic	5787	31.21	41	28.87	0.71	5746	31.23	99.29	1.22 (.71–2.12)	.47	
White, non-Hispanic	3420	18.44	21	14.79	0.18	3399	18.47	99.39	Ref	Ref	
Other	671	3.62	6	4.23	3.13	665	3.61	99.11	1.83 (.75–4.42)	.18	
Neighborhood poverty level											
Low poverty (<10% below FPL)	1728	9.32	6	4.23	0.35	1722	9.36	99.65	Ref	Ref	
Medium (10% to <20% below FPL)	4814	25.96	33	23.24	0.69	4781	25.98	99.31	1.35 (.64–2.84)	.43	
High (20% to <30% below FPL)	4720	25.46	43	30.28	0.91	4677	25.42	99.09	1.82 (.88–3.78)	.11	
Very high poverty (≥30% below FPL)	4499	24.26	45	31.69	1	4454	24.21	99	1.68 (.80–3.53)	.17	
Area-based poverty level not available	2781	15	15	10.56	0.54	2766	15.03	99.46	0.69 (.24–1.97)	.49	

Abbreviations: AOR, adjusted odds ratio; CI, confidence interval; FPL, federal poverty level; HIV, human immunodeficiency virus; NYC, New York City; OCME, Office of Chief Medical Examiner; Ref, reference.

The text in bold are statistically significant.

## Data Analysis

A descriptive analysis of all new HIV diagnoses identified at OCME autopsy was performed, which included sex, age, race/ethnicity, neighborhood poverty level (defined by the proportion of the population living below the federal poverty level using income data from the 2007–2011 American Community Survey [ACS] for 2006–2009 and from the 2008–2012 ACS for 2010–2013) [6], marital status, education level, and underlying cause of death (as determined by OCME autopsy). Not all variables were available for all persons with HIV: marital status, education level, and underlying cause of death were obtainable only in the VSR and,

therefore, were available only for the decedents. Sex, age, race/ethnicity, and neighborhood poverty level variables were available in both HSR and VSR and, therefore, were available for the entire study population. We used multivariable logistic regression modeling to further characterize persons newly diagnosed with HIV infection at autopsy by comparing them to the following: (1) all persons newly diagnosed with HIV in NYC and (2) all persons autopsied by the NYC OCME who tested positive for HIV. Results of multivariable modeling are presented as adjusted odds ratios (AORs) with 95% confidence intervals (95% CIs). Separate logistic regression models were constructed for each comparison.

**Table 2. Newly Diagnosed HIV Infection at OCME Autopsy Among All HIV-Infected OCME Autopsies in Persons 13 Years and Older in NYC, 2008–2012**

	All HIV OCME Autopsies		HIV Infection						AOR (95% CI)	P Value
			Newly Diagnosed at OCME Autopsy			Already Diagnosed During Life				
	N	%	N	Column %	Row %	N	Column %	Row %		
Total	1623	100	142	100	8.75	1481	100	91.25	—	—
Sex										
Male	1169	72.03	105	73.94	8.98	1064	71.84	91.02	0.89 (.57–1.38)	.6
Female	454	27.97	37	26.06	8.15	417	28.16	91.85	Ref	Ref
Age										
13–64	1532	94.39	122	85.92	7.96	1410	95.21	92.04	Ref	Ref
≥65	<b>91</b>	<b>5.61</b>	<b>20</b>	<b>14.08</b>	<b>21.98</b>	<b>71</b>	<b>4.79</b>	<b>78.02</b>	<b>4.17 (2.06–8.42)</b>	<b>&lt;.0001</b>
Race/ethnicity										
Black, non-Hispanic	822	50.65	74	52.11	9	748	50.51	91	1.83 (.94–3.55)	.07
Hispanic	480	29.57	41	28.87	8.54	439	29.64	91.46	1.78 (.87–3.64)	.11
White, non-Hispanic	280	17.25	21	14.79	7.5	259	17.49	92.5	Ref	Ref
Other	41	2.53	6	4.23	14.63	35	2.36	85.37	2.44 (.86–6.92)	.09
Neighborhood poverty level										
Low poverty (<10% below FPL)	122	7.52	6	4.23	4.92	116	7.83	95.08	Ref	Ref
Medium (10 to <20% below FPL)	348	21.44	33	23.24	9.48	315	21.27	90.52	1.46 (.53–4.01)	.47
High (20 to <30% below FPL)	473	29.14	43	30.28	9.09	430	29.03	90.91	1.21 (.44–3.35)	.72
Very high poverty (≥30% below FPL)	602	37.09	45	31.69	7.48	557	37.61	92.52	1.38 (.51–3.74)	.53
Area-based poverty level not available	78	4.81	15	10.56	19.23	63	4.25	80.77	6.06 (2.14–17.22)	.0007
Marital status										
Single/divorced/separated	1237	76.22	116	81.69	9.38	1121	75.69	90.62	1.21 (.62–2.37)	.57
Married	166	10.23	16	11.27	9.64	150	10.13	90.36	Ref	Ref
Unknown	220	13.56	10	7.04	4.55	210	14.18	95.45	0.99 (.32–3.13)	.99
Education										
Less than college	<b>1294</b>	<b>79.73</b>	<b>119</b>	<b>83.8</b>	<b>9.2</b>	<b>1175</b>	<b>79.34</b>	<b>90.8</b>	<b>2.61 (1.39–4.91)</b>	<b>.003</b>
College or more than college	128	7.89	16	11.27	12.5	112	7.56	87.5	Ref	Ref
Unknown	201	12.38	7	4.93	3.48	194	13.1	96.52	0.31 (.09–1.05)	.06
Cause of death										
HIV-related death	<b>221</b>	<b>13.62</b>	<b>24</b>	<b>16.9</b>	<b>10.86</b>	<b>197</b>	<b>13.3</b>	<b>89.14</b>	<b>3.38 (2.06–5.54)</b>	<b>&lt;.0001</b>
Natural death, non-HIV related	792	18.8	71	50	8.96	721	48.08	91.04	Ref	Ref
Unnatural death	610	37.58	47	33.1	7.7	563	38.01	92.3	1.22 (.76–1.97)	.41

Abbreviations: AOR, adjusted odds ratio; CI, confidence interval; FPL, federal poverty level; HIV, human immunodeficiency virus; NYC, New York City; OCME, Office of Chief Medical Examiner; Ref, reference. The text in bold are statistically significant.

Variables with epidemiologic significance were included in the models. All analyses were carried out using SAS 9.2 (Cary, NC).

## RESULTS

From 2008 through 2012, there were 264 893 deaths in NYC, of which 24 426 (9.2%) decedents were autopsied by the NYC OCME. Among the decedents autopsied, 1623 (6.6%) were infected with HIV. Of these HIV-infected decedents, 142 (8.8%) were newly diagnosed with HIV infection at OCME autopsy (Figure 1).

### **Characteristics of Persons Newly Diagnosed With Human Immunodeficiency Virus at Office of Chief Medical Examiner Autopsy**

Among the 142 newly HIV-diagnosed decedents, 73.9% were male, 14.1% were  $\geq 65$  years, 52.1% were black, and 28.9% were Hispanic (Tables 1 and 2). More than half (62.0%) were, at the time of their death, residing in a neighborhood classified as having a high or very high poverty rate (Tables 1 and 2). Most (81.7%) were unmarried (single, divorced, or widowed) and had less than a college education (83.8%) (Table 2).

### **Newly Diagnosed With Human Immunodeficiency Virus (HIV) Infection at Office of Chief Medical Examiner Autopsy: Comparison to All Newly Diagnosed With HIV**

There were 18 542 persons newly diagnosed with HIV infection in NYC from 2008 through 2012 including the 142 identified at autopsy. The 142 decedents newly diagnosed with HIV infection at OCME autopsy accounted for 0.8% of all new HIV diagnoses in NYC during this period. The percentage of new HIV infection diagnoses made at OCME autopsy was 7.6 times as high among decedents aged  $\geq 65$  (20 of 390, 5.1%) as among those aged 13–64 (122 of 18 030, 0.67%). After controlling for sex, race/ethnicity, and neighborhood poverty rate, newly HIV infected persons  $\geq 65$  years were much more likely (AOR = 7.7; 95% CI, 4.7–12.5) to be newly diagnosed at OCME autopsy than newly infected persons aged 13–64 years (Table 1).

### **Newly Diagnosed With Human Immunodeficiency Virus (HIV) Infection at Office of Chief Medical Examiner (OCME) Autopsy: Comparison to All HIV-Infected Persons Undergoing OCME Autopsy**

Of the OCME autopsied HIV-infected persons, the percentage of new HIV infection diagnoses made at autopsy among decedents aged  $\geq 65$  was almost 3 times (20 of 91, 22%) as high as among those aged 13–64 (122 of 1532, 8%). After controlling for sex, race/ethnicity, neighborhood poverty rate, marital status, education, and cause of death, the decedents newly diagnosed at OCME autopsy were more likely to be  $\geq 65$  years (AOR = 4.2; 95% CI, 2.1–8.4), have less than a college education (AOR = 2.6; 95% CI, 1.4–4.9), and have died of an HIV-related cause (AOR = 3.4; 95% CI, 2.1–5.5) than other HIV-infected persons undergoing OCME autopsy (Table 2).

## DISCUSSION

By using a longstanding practice in NYC of routine HIV testing of all persons undergoing autopsy by the Chief Medical Examiner, and the ability to link these data to the population-based HSR, we established that approximately 30 decedents each year are newly diagnosed with HIV at OCME autopsy. These HIV-infected decedents, accounting for 8.8% of all HIV-infected decedents autopsied by OCME, were not diagnosed while alive despite intense citywide efforts to promote and expand HIV testing. We found that age  $\geq 65$  years was independently associated with new HIV diagnosis at OCME autopsy among both all new HIV diagnoses and all HIV-infected OCME autopsies, a finding that can be instructive to ongoing efforts to expand HIV testing and diagnose HIV earlier in its course.

Our finding that age  $\geq 65$  years was independently associated with new diagnosis at OCME autopsy is consistent with other North American data showing that older adults are more likely to be diagnosed at a late stage of HIV infection than their younger counterparts [18–23]. This finding, underscored by local NYC surveillance data showing a high proportion (44%) of late HIV diagnosis among newly HIV-diagnosed persons age  $\geq 65$  years in NYC (NYC DOHMH; unpublished data), suggests that a subset of HIV-infected-but-undiagnosed older adults are particularly challenging to reach with HIV screening efforts.

There are several possible explanations for this finding. Current guidelines for HIV testing in healthcare settings recommend routine HIV screening for all individuals aged 13–64 but do not include those who are  $\geq 65$  [24]. Although detailed clinical information is not available in our analysis, these results suggest that HIV infection was not considered during life. This oversight might be attributable to a combination of inaccurate self-perceptions of risk among older adults and incomplete understanding by practitioners that, although HIV testing need not be routinely offered to those  $> 65$  and older, all patients should still be screened for risk, and among those with risk, HIV testing should be offered regardless of age [25–28].

This analysis has a number of limitations. Ascertainment of late diagnosis is based on information from the HSR; it is possible that there may have been decedents who knew their HIV status through anonymous HIV testing. In addition, there may have been decedents who knew their HIV status from having been diagnosed in yet another jurisdiction. Finally, our study could only capture those previously undiagnosed, HIV-infected decedents who were autopsied by OCME. There could have been undiagnosed HIV-infected decedents who did not have OCME autopsies; they remain undiagnosed in the methodology we used.

## CONCLUSIONS

Human immunodeficiency virus diagnosis as early as possible in the course of HIV infection has long been a public health

goal. Using a novel study design that leverages a unique testing policy, we identified 142 persons who died in NYC over a 5-year period having never been diagnosed with HIV infection while alive, thus providing a vivid illustration of the challenge of complete attainment of this goal. The HIV testing law of the NYS DOH (Chapter 308 of the Laws of 2010) requires offering HIV testing to all those between the ages of 13 and 64. There are currently no recommendations for routine HIV testing for adults  $\geq 65$ . Although our findings may suggest the need to expand the age recommendation, the data are not sufficient to form a basis for a policy recommendation. Nonetheless, the question of whether gaps remain in the effort to diagnose HIV early in its course among persons  $\geq 65$  warrants further study.

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**Potential conflicts of interest.** All authors: No reported conflicts.

All authors have submitted the ICMJE Form for Disclosure of Potential Conflicts of Interest.

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