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Care and viral suppression during the last year of life among persons with HIV who died in 2012, 18 U.S. jurisdictions

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Abstract

Death due to HIV remains a leading cause of death among some U.S. populations, yet little is known about HIV care before death. We used data from the National HIV Surveillance System to determine disease stage and care within 12 months prior to death among persons infected with HIV who died in 2012. Persons were considered to be in care within 12 months before death if they had ≥1 CD4 or viral load test results, and in continuous care if they had ≥2 CD4 or viral load test results at least 3 months apart. Viral suppression (viral load <200 copies/mL) was based on the most recent viral load test result in the 12 months before death. Among 7,348 persons infected with HIV who died in 2012, 47.1% had late stage disease (AIDS) within 12 months before death. Overall, 85.7% had ≥1 test result, 64.3% had ≥2 tests at least 3 months apart, and 41.6% had a suppressed viral load. While blacks and Hispanics/Latinos had higher percentages of continuous care compared with whites, they had lower percentages of viral suppression and higher percentages with late-stage disease. Viral suppression was higher among older persons. The majority had been diagnosed with HIV more than 5 years before death (86.3%). Although the majority of persons infected with HIV who died in 2012 had been diagnosed many years before death, almost half had late-stage disease, and there were disparities in late stage disease and viral suppression by race/ethnicity and age.

Keywords

HIV; AIDS; death; care; treatment

Introduction

In 2010, there were about 8,400 deaths due to HIV infection in the United States and death due to HIV remains a leading cause of death among some U.S. populations (Centers for Disease Control and Prevention, 2014). Such deaths may reflect difficulties with accessing medical services, HIV treatment, and treatment adherence. While overall 87% of persons living with HIV have been diagnosed, about 24% persons have stage 3 disease (AIDS) at time of diagnosis, almost half of the persons living with diagnosed HIV are not in regular care and only 50% have a suppressed viral load (Centers for Disease Control and Prevention,

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2015a). Among patients in British Columbia who had initiated treatment, steep declines in CD4 counts and increased health care visits were observed in the 5 years before death, leading the authors to question whether better retention in care and treatment may have made deaths avoidable (Cui et al., 2014). Little information is available about care and care outcomes before death among persons living with HIV in the United States.

We used data from the U.S. National HIV Surveillance System to determine stage of disease, HIV care, and viral suppression within the year before death among persons living with HIV who died in 2012. These data can help focus public health action to improve retention in care and treatment among persons with HIV (Mermin & Fenton, 2012; Sweeney et al., 2013).

Methods

All states and the District of Columbia require reporting of cases of HIV infection to their health departments; however, not all have mandatory reporting of all values of CD4 cell counts and viral load test results by laboratories. We used data from 18 jurisdictions (California, District of Columbia, Hawaii, Illinois, Indiana, Iowa, Louisiana, Maryland, Michigan, Missouri, New Hampshire, New York, North Dakota, South Carolina, Texas, Utah, West Virginia, Wyoming) with mandatory laboratory reporting of all HIV-related tests and reporting of all tests to national HIV surveillance. The analysis included persons who were diagnosed in the selected areas, died in 2012 in the selected areas, and were ≥13 years old at time of death. Data were reported to national surveillance through June 2014.

Stage of disease was based on the most recent CD4 count or percentage (Selik, 2014). Persons were considered to be in care if they had ≥1 CD4 or viral load test results, and in continuous care if they had ≥2 CD4 or viral load test results at least 3 months apart, within the 12 months before death (The White House Office of National AIDS Policy, 2010). Viral suppression (defined as <200 copies/mL) was based on the most recent viral load test result in the 12 months before death.

We assessed indicators overall and by sex, age, race/ethnicity, and transmission category (male-to-male sexual contact [men who have sex with men, MSM], injection drug use, male-to-male sexual contact and injection drug use, heterosexual contact, and other). We also determined care and viral suppression by disease severity (whether a person's infection had ever been classified as stage 3, AIDS), the length of time since diagnosis of HIV infection, and urban versus rural area of residence at time of diagnosis (metropolitan statistical area population ≥500,000; metropolitan area 50,000 to 499,999; and non-metropolitan). We compared groups with prevalence ratios adjusted for other potential covariates and calculated 95% confidence intervals. Analyses were adjusted for missing risk factor information (Centers for Disease Control and Prevention, 2015b).

Results

In 2012, there were 7,348 deaths among persons living with HIV in the 18 jurisdictions. The majority were male (74.8%); 40 years or older at the time of death (86.9%); black (45.5%), Hispanic or Latino (19.6%) or white (28.0%); or MSM (39.9%) (Table 1). Almost half of

the persons with HIV who died in 2012 had indication of late stage disease in the 12 months before death. The percentage with late stage disease was higher among younger persons aged 20–39, all race/ethnicity groups compared with whites, and those infected perinatally.

Overall, 85.7% of persons who died had ≥1 CD4 or viral load test, 64.3% had ≥2 tests at least 3 months apart, and 41.6% had a suppressed viral load (Table 2). The percentage with ≥1 test was close to 80% or higher among all groups, except 64.4% had ≥1 tests among those never diagnosed with stage 3, AIDS, compared to those with disease ever classified as stage 3 (89.9%). Continuous care was higher among blacks and Hispanics or Latinos compared with whites and among persons with infection attributed to injection-drug use compared with MSM, and lower among persons with disease ever classified as stage 3 (AIDS).

Except for those aged 13–19 years (9 deaths total), the percentage with viral suppression was lower among younger persons compared with older persons (Table 2). Prevalence of viral suppression was also lower among blacks compared with whites, persons with HIV infection attributed to heterosexual contact compared with MSM, and persons who never had late stage disease.

The majority of persons who died in 2012 had been diagnosed with HIV more than 5 years before death (5,720 of 7,348 persons who died, 77.8%); 55.6% had disease classified as stage 3 (AIDS) more than 5 years before death and 16.5% never had severe disease (data not shown). Among the 699 persons who had been diagnosed with HIV within 12 months before death, 74.8% had disease classified as stage 3 (AIDS) in the same time period.

Discussion

The majority of persons who died had their HIV infection diagnosed more than 5 years before death and had late-stage disease (AIDS) at some point in time, yet only 4 in 10 had a suppressed viral load. Almost half of those who died had late stage disease during the last 12 months of life. Persons with late-stage disease or who did not have a suppressed viral load may represent persons who did not receive adequate care and treatment or patients with treatment failure. Factors that contribute to risk of death among persons with treatment failure include older age, injection-drug use, and a first-line therapy with protease inhibitors (Palella et al., 2014). However, the high percentage with late-stage disease among those diagnosed with HIV within 12 months of death points to issues with delayed diagnosis and initiation of treatment.

The percentage in continuous care or with viral suppression was lower among younger compared with older persons, consistent with findings for persons living with HIV (Hall et al., 2013; Brennan, Morley, O’Leary, Bergin, & Horgan, 2014). However, compared to young persons living with HIV, a higher percentage of young persons who died received HIV care, possibly because they had symptoms. The percentage of blacks diagnosed late is comparable to that of whites (Centers for Disease Control and Prevention, 2015a); however, at the time of death the percentage with late stage disease was higher among blacks. Generally, blacks have a lower percentage promptly linked to care after diagnosis

compared with whites (Centers for Disease Control and Prevention, 2015a), and among persons in HIV care, a lower percentage of blacks receive a prescription of HAART or achieve viral suppression (Centers for Disease Control and Prevention, 2011). HIV care and treatment may be covered by private or public health insurance or the Ryan White HIV/AIDS Program (RWHAP), with patients who receive RWHAP supplementation including non-medical support services more likely to be prescribed treatment and have suppressed viral loads regardless of the their health insurance status (Bradley et al., 2015). Insurance type and non-medical support services are particularly important for persons living with HIV as factors that may influence care, treatment, and viral suppression not only include access to care, prescription patterns, and treatment adherence but also other socioeconomic barriers (Beer et al., 2014; Horstman, Brown, Islam, Buck, & Agins, 2010; Wohl et al., 2011).

This analysis was subject to several limitations. Data were available for 18 U.S. jurisdictions, representing 50% of all persons with HIV aged ≥13 years who died during 2012 in the United States, and may not be representative of all persons with HIV who died in the United States that year. Information was not available on comorbidity, prescription of HAART or treatment adherence. Conclusions cannot be drawn on the cause of death; however, these data indicate many persons who died had advanced disease, and cause of death information from death certificates may underestimate deaths due to HIV (Chu et al., 1993; Hessol et al., 1992). CD4 and viral load testing reflect HIV care but may not adequately capture end-of-life care.

Improving outcomes along the continuum of care should help avoid deaths from HIV in the future. Ensuring early initiation of treatment regardless of stage of disease as recommended in the current treatment guidelines (Panel on Antiretroviral Guidelines for Adults and Adolescents, 2014), and providing support so that people stay in care and on treatment, would reduce the number of deaths caused by HIV (Wada et al., 2014) and allow persons with HIV to have a similar life expectancy to persons without HIV (Samji et al., 2013).

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Table 1.

Stage of disease within 12 months before death, among persons aged 13 years and older who died in 2012, by selected characteristics—18 U.S. jurisdictions

	Stage 1 (CD4 ≥ 500 cells/μL or ≥ 29%)		Stage 2 (CD4 200–499 cells/μL or 14%–28%)		Stage 3 (AIDS) (OI or CD4 < 200 cells/μL or < 14%)		Unknown		Total	
	(No.)	(%)	(No.)	(%)	(No.)	(%)	(No).	(%)	(No.)	(%)
Sex										
Male	704	12.8	1,247	22.7	2,594	47.2	954	17.3	5,499	74.8
Female	295	16.0	417	22.6	864	46.7	273	14.8	1,849	25.2
Age at death, year-end 2012										
13–19	2	22.2	1	11.1	4	44.4	2	22.2	9	0.1
20–29	27	10.4	39	15.0	160	61.5	34	13.1	260	3.5
30–39	70	10.1	107	15.5	431	62.5	82	11.9	690	9.4
40–49	232	12.1	355	18.5	1,031	53.9	296	15.5	1,914	26.0
50–59	383	14.3	651	24.3	1,200	44.8	443	16.5	2,677	36.4
>=60	285	15.9	511	28.4	632	35.2	370	20.6	1,798	24.5
Race/Ethnicity										
American Indian/Alaska Native	0	0	0	0	4	80.0	1	20.0	5	0.1
Asian	3	6.8	9	20.5	25	56.8	7	15.9	44	0.6
Black/African American	421	12.6	726	21.7	1,662	49.7	536	16.0	3,345	45.5
Hispanic/Latino[a]	159	11.1	331	23.0	745	51.8	203	14.1	1,438	19.6
Native Hawaiian/Other Pacific Islander	0	0	1	33.3	2	66.7	0	0	3	0
White	339	16.5	487	23.7	802	39.0	427	20.8	2,055	28.0
Multiple races	77	16.8	110	24.0	218	47.6	53	11.6	458	6.2
Transmission Category[b]										
Male-to-male sexual contact	397	13.5	642	21.9	1,402	47.8	491	16.8	2,933	39.9
Male injection drug use	153	11.7	322	24.7	602	46.1	229	17.5	1,306	17.8
Female Injection drug use	123	16.3	193	25.5	320	42.4	120	15.8	756	10.3
Male-to-male sexual contact and injection drug use	78	12.6	157	25.5	278	45.0	105	16.9	618	8.4
Male Heterosexual contact	70	11.8	113	19.1	289	48.9	119	20.2	591	8.0

	Stage 1 (CD4 ≥ 500 cells/μL or ≥ 29%)		Stage 2 (CD4 200–499 cells/μL or 14%–28%)		Stage 3 (AIDS) (OI or CD4 < 200 cells/μL or < 14%)		Unknown		Total	
	(No.)	(%)	(No.)	(%)	(No.)	(%)	(No).	(%)	(No.)	(%)
Female Heterosexual contact	169	15.9	217	20.5	527	49.7	148	14.0	1,061	14.4
Male Other	5	15.7	7	25.8	11	39.4	6	19.2	29	0.4
Female Other	3	31.8	4	37.4	1	10.3	2	20.6	11	0.1
Perinatal	2	4.5	8	18.2	27	61.4	7	15.9	44	0.6
Ever AIDS										
Yes	617	10.1	1,336	21.8	3,458	56.3	726	11.8	6,137	83.5
No	382	31.5	328	27.1	0	0	501	41.4	1,211	16.5
Total	999	13.6	1,664	22.6	3,458	47.1	1,227	16.7	7,348	100

Abbreviations: CD4, CD4+ T-lymphocyte count (cells/μL) or percentage; OI, opportunistic infection (i.e., AIDS-defining condition).

Note. Stage of disease within 12 months of death based on most recent CD4 test performed.

[a] Hispanics/Latinos can be of any race.

[b] Data by transmission category have been statistically adjusted to account for missing transmission category.

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Table 2.

Care and viral suppression within 12 months before death, among persons aged >12 years who died in 2012, by selected characteristics—18 U.S. jurisdictions

	Total	≥1 CD4/VL		≥2 CD4/VL, at least 3 months apart				Viral load <200 copies/mL			
	(No.)	(No.)	(%)	(No.)	(%)	PR[a]	95% CI	(No.)	(%)	PR[a]	95% CI
Sex											
Male	5,499	4,688	85.3	3,495	63.6	-		2,378	43.2	-	
Female	1,849	1,612	87.2	1,232	66.6	-		682	36.9	-	
Age at death year-end 2012											
13–19	9	8	88.9	4	44.4	0.70	0.34, 1.42	6	66.7	1.12	0.64, 1.96
20–29	260	227	87.3	157	60.4	0.92	0.82, 1.03	56	21.5	0.4	0.31, 0.52
30–39	690	615	89.1	414	60.0	0.92	0.86, 0.99	178	25.8	0.52	0.45, 0.59
40–49	1,914	1,666	87.0	1,212	63.3	0.96	0.92, 1.01	706	36.9	0.71	0.66, 0.76
50–59	2,677	2,309	86.3	1,773	66.2	1.00	0.96, 1.05	1,184	44.2	0.85	0.80, 0.91
>=60	1,798	1,475	82.0	1,167	64.9	-		930	51.7	-	
Race/Ethnicity											
American Indian/Alaska Native	5	5	100.0	3	60.0	0.99	(0.50, 1.98)	2	40.0	0.79	(0.27, 2.32)
Asian	44	38	86.4	24	54.5	0.95	(0.73, 1.24)	19	43.2	0.93	(0.67, 1.29)
Black/African American	3,345	2,871	85.8	2,181	65.2	1.08	(1.03, 1.13)	1,214	36.3	0.80	(0.75, 0.86)
Hispanic/Latino[b]	1,438	1,261	87.7	965	67.1	1.11	(1.05, 1.16)	629	43.7	0.96	(0.89, 1.03)
Native Hawaiian/Other Pacific Islander	3	3	100.0	2	66.7	1.52	(0.62, 3.75)	1	33.3	0.84	(0.18, 3.88)
White	2,055	1,706	83.0	1,231	59.9	-		996	48.5	-	
Multiple races	458	416	90.8	321	70.1	1.15	(1.07, 1.23)	199	43.4	0.92	(0.82, 1.03)
Transmission Category[c]											
Male-to-male sexual contact	2,933	2,528	86.2	1,816	61.9	-		1,282	43.7	-	
Male injection drug use	1,306	1,113	85.2	891	68.3	1.06	(1.01, 1.11)	588	45.1	1.0	(0.93, 1.08)
Female Injection drug use	756	655	86.7	527	69.7	1.10	(1.04, 1.16)	296	39.2	0.93	(0.84, 1.02)
Male-to-male sexual contact and injection drug use	618	524	84.7	409	66.1	1.04	(0.98, 1.10)	282	45.5	1.04	(0.95, 1.14)
Male Heterosexual contact	591	480	81.3	348	58.9	0.95	(0.88, 1.02)	203	34.5	0.81	(0.72, 0.91)
Female Heterosexual contact	1,061	931	87.7	682	64.2	1.04	(0.99, 1.10)	371	35.0	0.88	(0.80, 0.97)
Male Other	29	24	84.3	17	60.6	0.96	(0.72, 1.29)	14	50.2	1.02	(0.72, 1.46)

	Total	≥1 CD4/VL		≥2 CD4/VL, at least 3 months apart				Viral load <200 copies/mL			
	(No.)	(No.)	(%)	(No.)	(%)	PR[a]	95% CI	(No.)	(%)	PR[a]	95% CI
Female Other	11	9	82.2	8	71.0	1.14	(0.80, 1.63)	6	58.9	1.14	(0.70, 1.85)
Perinatal	44	36	81.8	30	68.2	1.11	(0.89, 1.39)	16	36.4	1.46	(0.91, 2.35)
Ever AIDS											
Yes	6,137	5,520	89.9	4,163	67.8	-		2,585	42.1	-	
No	1,211	780	64.4	564	46.6	0.69	(0.65, 0.74)	475	39.2	0.92	(0.86, 0.99)
Number of years since diagnosis											
≤12 months	699	583	83.4	179	25.6	-		115	16.5	-	
13–24 months	231	204	88.3	160	69.3	-		98	42.4	-	
3–5 years	698	577	82.7	415	59.5	-		264	37.8	-	
more than 5 years	5,720	4,936	86.3	3,973	69.5	-		2,583	45.2	-	
MSA[d]											
MSA (population ≥500,000)	6,208	5,363	86.4	4,092	65.9	-		2,660	42.8	-	
Metropolitan area (population 50,000–499,999)	717	605	84.4	410	57.2	-		261	36.4	-	
Nonmetropolitan area	385	304	79.0	204	53.0	-		126	32.7	-	
Total	7,348	6,300	85.7	4,727	64.3	-		3,060	41.6	-	

Abbreviations: VL, viral load (copies/mL); PR, prevalence ratio; CI, confidence interval; MSA, metropolitan statistical area.

[a]Adjusted for age at death, race/ethnicity, transmission category, and ever AIDS.

[b]Hispanics/Latinos can be of any race.

[c]Data by transmission category have been statistically adjusted to account for missing transmission category.

[d]Data on county were missing for 38 persons; they could not be assigned to MSA category and are not included in the tabulation.

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