


## Original Investigation

# Differences in Human Immunodeficiency Virus Care and Treatment Among Subpopulations in the United States

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**IMPORTANCE** Early diagnosis of human immunodeficiency virus (HIV) infection, prompt linkage to and sustained care, and antiretroviral therapy are associated with reduced individual morbidity, mortality, and transmission of the virus. However, levels of these indicators may differ among population groups with HIV. Disparities in care and treatment may contribute to the higher incidence rates among groups with higher prevalence of HIV.

**OBJECTIVE** To examine differences between groups of persons living with HIV by sex, age, race/ethnicity, and transmission category at essential steps in the continuum of care.

**DESIGN AND SETTING** We obtained data from the National HIV Surveillance System of the Centers for Disease Control and Prevention to determine the number of persons living with HIV who are aware and unaware of their infection using back-calculation models. We calculated the percentage of persons linked to care within 3 months of diagnosis on the basis of CD4 level and viral load test results. We estimated the percentages of persons retained in care, prescribed antiretroviral therapy, and with viral suppression using data from the Medical Monitoring Project, a surveillance system of persons receiving HIV care in select areas representative of all such persons in the United States.

**PARTICIPANTS** All HIV-infected persons in the United States.

**MAIN OUTCOMES AND MEASURES** Percentage of persons living with HIV who are aware of their infection, linked to care, retained in care, receiving antiretroviral therapy, and achieving viral suppression.

**RESULTS** Of the estimated 1 148 200 persons living with HIV in 2009 in the United States, 81.9% had been diagnosed, 65.8% were linked to care, 36.7% were retained in care, 32.7% were prescribed antiretroviral therapy, and 25.3% had a suppressed viral load ( $\leq 200$  copies/mL). Overall, 857 276 persons with HIV had not achieved viral suppression, including 74.8% of male, 79.0% of black, 73.9% of Hispanic/Latino, and 70.3% of white persons. The percentage of blacks in each step of the continuum was lower than that for whites, but these differences were not statistically significant. Among persons with HIV who were 13 to 24 years of age, only 40.5% had received a diagnosis and 30.6% were linked to care. Persons aged 25 to 34, 35 to 44, and 45 to 54 years were all significantly less likely to achieve viral suppression than were persons aged 55 to 64 years.

**CONCLUSIONS AND RELEVANCE** Significant age disparities exist at each step of the continuum of care. Additional efforts are needed to ensure that all persons with HIV receive a diagnosis and optimal care to reduce morbidity, mortality, disparities in care and treatment, and ultimately HIV transmission. Ensuring that people stay in care and receive treatment will increase the proportion of HIV-infected individuals who achieve and maintain a suppressed viral load.

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Early diagnosis of human immunodeficiency virus (HIV) infection, prompt linkage to and sustained care, and antiretroviral therapy (ART) are associated with reduced morbidity and mortality and onward transmission of the virus.<sup>1</sup> However, optimal outcomes along the continuum of care have not been achieved. Of the more than 1.1 million persons living with HIV in the United States, more than 200 000 are unaware of their infection,<sup>2</sup> less than 50% of persons with HIV are in regular care, and less than 30% have a suppressed viral load.<sup>1</sup> In addition, disparities may exist in access to HIV testing, care, and treatment between population groups.

Achieving a high percentage of coverage in each step of the continuum of care for persons with HIV is essential in a comprehensive strategy to address HIV in the United States. Persons aware of their HIV infection are less likely to transmit HIV, with about 51% of the estimated 50 000 new infections per year attributed to 80% of persons with HIV aware of their infection compared with 49% of new infections attributed to 20% of persons with HIV who were unaware of their infection in 2008.<sup>3</sup> Persons who are not linked to care after diagnosis or who do not establish and remain in regular care are at increased risk for premature mortality because they are less likely to receive ART, and those prescribed ART have worse treatment adherence.<sup>4-7</sup> Persons who do not receive a diagnosis or care also cannot benefit from some additional prevention activities designed to reduce HIV transmission, including screening and counseling for risk behaviors and diagnosis and treatment of sexually transmitted diseases.<sup>8</sup> All steps in the continuum are required for a strategy incorporating treatment as prevention.

Human immunodeficiency virus disproportionately affects blacks or African Americans (hereafter referred to as blacks) and Hispanics or Latinos, injection drug users, and gay, bisexual, and other men who have sexual contact with men (MSM contact).<sup>9</sup> Factors associated with disparities in HIV incidence may also be associated with disparities in the continuum of care; that is, disparities in care and treatment may contribute to the higher incidence rates among groups with a higher prevalence of HIV. Our objectives were to provide updated estimates for the continuum of care using surveillance data and to add an examination of differences between groups of persons living with HIV by sex, age, race/ethnicity, and transmission category at essential steps in the continuum of care.

## Methods

We used data from 2 national surveillance systems to determine the percentage of persons living with HIV in each step of the continuum of care. Data from the National HIV Surveillance System were used to determine HIV prevalence, that is, the total number of persons living with HIV (diagnosed or undiagnosed). National surveillance data were also used to determine the percentage of persons linked to care. Data from the Medical Monitoring Project (MMP) were used to determine the percentage of persons with HIV retained in care, prescribed ART, and achieving viral suppression.

To determine the prevalence of diagnosed and undiagnosed HIV infection, we used HIV and AIDS data for adults and adolescents (persons aged  $\geq 13$  years at diagnosis) from 46 states that had confidential name-based HIV infection reporting as of January 2007 and AIDS data only from the District of Columbia and the 4 other states (Hawaii, Maryland, Massachusetts, and Vermont). The estimates for the overall and undiagnosed HIV prevalence were obtained in 4 steps. First, HIV and AIDS data were statistically adjusted to mitigate the effects of (1) delays in reporting new cases and deaths, (2) incomplete reporting of diagnosed cases, and (3) cases reported without sufficient risk factor information to be classified into an HIV transmission category.<sup>2,10,11</sup> Second, based on the estimated annual number of HIV diagnoses and the severity of disease at diagnosis (ie, whether the person received an AIDS diagnosis in the same calendar year as the HIV diagnosis), an extended back-calculation model was fitted to estimate the cumulative number of persons 13 years or older who had been infected with HIV by the end of 2009.<sup>10,11</sup> Third, the estimated overall HIV prevalence was calculated by subtracting the estimated cumulative number of deaths that had occurred among those infected by the end of 2009 from the estimated cumulative number of HIV infections. Finally, the undiagnosed HIV prevalence was calculated by subtracting the estimated number of diagnosed HIV infections in living persons from the estimated overall HIV prevalence.

Linkage to care was determined on the basis of data from 14 jurisdictions (Delaware, Illinois, Indiana, Iowa, Minnesota, Missouri, Nebraska, New York [excluding New York City], North Dakota, South Carolina, West Virginia, Wyoming, the District of Columbia, and San Francisco, California) with complete reporting of CD4 levels and viral load test results to the National HIV Surveillance System. Using data for persons diagnosed in 2010 and data reported to the Centers for Disease Control and Prevention (CDC) through December 31, 2011, we determined linkage to care, defined as having had at least 1 measurement of a CD4 level or 1 viral load test result within 3 months after diagnosis.

The MMP is a cross-sectional survey with a 3-stage sampling design to obtain nationally representative estimates of HIV-infected adults receiving medical care. First, 17 states or territories (California, Delaware, Florida, Georgia, Illinois, Indiana, Michigan, Mississippi, New Jersey, New York, North Carolina, Oregon, Pennsylvania, Puerto Rico, Texas, Virginia, and Washington) were sampled with probability proportionate to size from the 50 US states, the District of Columbia, and Puerto Rico. At the second stage, outpatient HIV care facilities were selected within participating states or territories. At the third stage, HIV-infected adults who had at least 1 medical care visit between January 1 and April 30, 2009, within the sampled facilities were selected. Data were collected through medical record review and face-to-face interview. Information on clinical care, such as prescription of ART and documentation of viral suppression in the 12 months preceding the interview, was obtained by medical record review. Information on patient demographic characteristics and risk behaviors was collected by face-to-face interviews from June 1, 2009, through May 31, 2010.<sup>12-14</sup> The facility-level response rate was

76.5%, and the adjusted patient-level response rate was 50.7%. Patients who had at least 1 medical care visit from January through April of 2009 were considered to be retained in care. Prescription of ART was defined as documentation in the medical record of any ART prescription in the past 12 months, and viral suppression was defined as documentation in the medical record of the most recent viral load as undetectable or no greater than 200 copies/mL.

Population estimates using MMP data were weighted for the probability of selection and adjusted for nonresponse. The sum of weights was used to estimate the number of HIV-infected adults who received at least 1 medical care visit from January through April of 2009; these data were used to estimate the number of persons retained in care in 2009.

We determined the percentages of persons with HIV in the steps of the continuum of care (diagnosis, linkage to care, retained in care, prescription of ART, and achievement of viral load suppression) based on appropriate denominators consisting of segments of the total respective population living with HIV by race/ethnicity (black, Hispanic or Latino, and white; numbers were too low to include other racial/ethnic groups), sex, age group, and transmission category (MSM contact, injection drug use, MSM contact and injection drug use, and heterosexual contact). Differences between comparison groups by percentage are described as observed. To determine whether differences in the ultimate outcome, viral suppression, were statistically significant, we used the delta method to derive the standard error for the percentage in care, receiving ART, or achieving viral suppression in a given subpopulation and for the difference in percentages between 2 subpopulations. These standard errors were used to conduct significance testing.<sup>15</sup> We did not have data from the MMP that corresponded to the prevalence group aged 13 to 24 years because the MMP includes only persons 18 years or older, and prevalence could not be determined by smaller age strata owing to sample size limitations.

In addition to the cumulative percentage of persons engaged in care along the continuum (ie, among all persons living with HIV as the denominator), we assessed the percentage of persons engaged in selected steps of the continuum among those engaged in the preceding step, that is, the percentages (1) diagnosed as having HIV among persons living with HIV; (2) retained in care among persons living with diagnosed HIV; (3) receiving ART among those retained in care; and (4) achieving viral suppression among those receiving ART. Not all steps in the continuum of care are necessarily dependent on the previous step. Persons living with HIV could have skipped the step of linkage to care within 3 months of diagnosis but could be represented in the following steps. Persons who did not receive a diagnosis, who were not linked to or in care, or who did not receive ART were assumed to have unsuppressed viral loads. A small percentage of persons achieve viral suppression without treatment; however, this finding has not been quantified.

## Results

In 2009, an estimated 1 148 200 people were living with HIV in the United States, of whom 18% had not received a diag-

nosis (Table 1). Among persons living with HIV, an estimated 44% were black; 19%, Hispanic or Latino; and 33%, white. Most persons living with HIV (61%) were 35 to 54 years of age; 7%, 13 to 24 years of age (the youngest group); and 15%, 25 to 34 years of age. Male individuals constituted 76% of the population. An estimated 52% of this population had infections attributed to MSM contact (an additional 5% had infection attributed to MSM contact and injection drug use), and 18% were female with infection attributed to heterosexual contact.

Among all persons living with HIV in 2009, 82% had been diagnosed as having HIV infection, 66% were linked to care, 37% were retained in care, 33% were prescribed ART, and 25% had a suppressed viral load (Table 1). Although some differences in awareness status and linkage to and retention in care were evident, the percentages of male and female persons who had a suppressed viral load were similar ( $P = .81$ ).

The percentages of blacks and Hispanics or Latinos who were aware of their infection were lower than that percentage among whites, and the percentages linked to care, retained in care, prescribed ART, and with a suppressed viral load were also lower among blacks compared with whites (Figure 1). Among blacks, 21% had a suppressed viral load compared with 30% among whites, although this difference was not statistically significant ( $P = .07$ ). Among Hispanics or Latinos, the percentages retained in care, prescribed ART, and with a suppressed viral load were lower than among whites, but the difference in viral suppression was not statistically significant ( $P = .51$ ).

Higher percentages of male (90%) and female (91%) persons with infection attributed to injection drug use and male persons with infection attributed to MSM contact and injection drug use (91%) were aware of their infection compared with persons in other transmission categories, including 82% among female persons with infection attributed to heterosexual contact, 79% among male persons with infection attributed to MSM contact, and 76% among male persons with infection attributed to heterosexual contact. Linkage to care followed a similar pattern (Table 1). The percentages with a suppressed viral load were similar for female persons with infection attributed to heterosexual contact (25%) or injection drug use (28%) and for male persons with infection attributed to MSM contact (27%) or to MSM contact and injection drug use (26%); percentages were lower for male persons with infection attributed to injection drug use (22%) or heterosexual contact (19%). Male persons with infection attributed to heterosexual contact were significantly less likely to achieve viral suppression than were male persons with infection attributed to MSM contact ( $P = .04$ ).

Lower percentages of younger persons were aware of their infection or linked to care than were those in older age groups (Figure 2). Lower percentages of persons aged 25 to 34 and 35 to 44 years were retained in care, were prescribed ART, and had a suppressed viral load than were persons aged 55 to 64 years. For example, among persons 25 to 34 years old, 28% were in care compared with 46% among those aged 55 to 64 years; 22% were prescribed ART compared with 42% among those

Table 1. Estimated Numbers of Persons Living With HIV in 2009 and Percentage in the Continuum of Care by Selected Characteristics, United States

Characteristic	Total, No. (%) <sup>a</sup>	Continuum of Care, % of Persons With HIV					P Value
		Diagnosed	Linked to Care	Retained in Care	Prescribed ART	Achieved Suppressed Viral Load	
Total	1 148 200 (100)	82	66	37	33	25	
Sex							
Male	869 000 (76)	81	65	35	32	25	<sup>b</sup>
Female	279 100 (24)	85	70	41	36	26	.81
Race/ethnicity							
Black	510 600 (44)	81	62	34	29	21	.07
Hispanic or Latino	220 400 (19)	80	67	37	33	26	.51
White	380 300 (33)	85	71	38	35	30	<sup>b</sup>
Transmission category							
MSM contact	592 100 (52)	79	63	36	33	27	<sup>b</sup>
Injection drug use							
Male	113 200 (10)	90	70	32	29	22	.20
Female	70 200 (6)	91	73	44	39	28	.82
MSM contact and injection drug use	60 200 (5)	91	76	39	35	26	.91
Heterosexual contact							
Male	100 600 (9)	76	60	29	26	19	.04
Female	207 100 (18)	82	68	40	34	25	.62
Age group, y							
13-24	76 400 (7)	41	31				
25-34	175 000 (15)	72	56	28	22	15	<.001
35-44	319 900 (28)	85	70	35	31	22	<.001
45-54	380 900 (33)	89	75	43	39	31	.18
55-64	155 700 (14)	89	74	46	42	36	<sup>b</sup>
≥65	40 300 (4)	89	73	35	33	27	.07

Abbreviations: ART, antiretroviral therapy; HIV, human immunodeficiency virus; MSM, male-to-male sexual contact.

<sup>a</sup> Numbers of persons have been estimated and may not sum totals.

<sup>b</sup> Indicates reference category.

aged 55 to 64 years; and 15% had a suppressed viral load compared with 36% among those aged 55 to 64 years. The percentage of persons who achieved a suppressed viral load was significantly lower among persons aged 25 to 34 years ( $P < .001$ ) and 35 to 44 years ( $P < .001$ ) than among persons aged 55 to 64 years.

In addition to cumulative changes noted along the continuum of engagement in care, we assessed differences at each step of the continuum among population groups (Table 2). Although a larger percentage of female (85%) than male (81%) persons with HIV had received a diagnosis, and among those with a diagnosis, a larger percentage of female (49%) than male (43%) persons were retained in care, among those retained in care a smaller percentage of female (86%) than male (90%) persons were prescribed ART. Among those prescribed ART, a smaller percentage of female (73%) than male (80%) persons had a suppressed viral load. Looking at each step of the continuum independently, blacks had lower percentages than whites at each step of the continuum. Similarly, persons aged 25 to 34, 35 to 44, and 45 to 54 years all had lower percentages than persons aged 55 to 64 years at each step of the continuum.

## Discussion

More than 850 000 persons with HIV did not have a suppressed viral load, including 79% of blacks, 74% of Hispanics or Latinos, and 70% of whites. Young persons were less likely to have received a diagnosis<sup>2</sup> or to have a suppressed viral load. Although the percentages were lower in each step of the continuum for blacks, we did not find significant differences in viral load suppression among race/ethnicity groups. However, as previously reported by the National HIV Surveillance System,<sup>2</sup> the percentage of individuals who were aware of their infection was significantly lower among blacks (80.6% [95% CI, 79.1%-82.0%]) and Hispanics or Latinos (80.3% [95% CI, 77.9%-82.5%]) compared with whites (85.2% [95% CI, 83.6%-86.7%]). Engaging all people with HIV in care and treatment is important for their optimum health and a comprehensive strategy to address HIV infection in the United States and the onward transmission of the virus.

The overall low rate of viral suppression could be attributed to the following 3 key factors: a large population of individuals in the United States are unaware of their infection;

among those who are aware of their HIV infection, only half are receiving regular care; and among those receiving care, not all are prescribed ART or optimally adhere to the treatment regimen. As noted in Table 2, success at each step of the continuum might differ between population groups; thus, different strategies might be needed in different groups to achieve optimal improvement at each step of the continuum of care. A primary factor that can affect access to and retention in care is lack of health insurance, with 32% of Latinos, 21% of blacks, and 16% of whites being uninsured.<sup>16</sup> Other barriers that have been associated with reduced access to care and treatment include lack of social support, competing child care responsibilities, food insecurity, unstable housing, lack of transportation, lower educational level, poverty, unemployment, homelessness, and mental health or substance abuse problems.<sup>17,18</sup> In addition, because gay, bisexual, and other men of all races who have MSM contact and blacks remain the populations most heavily affected by HIV in the United States, we must under-

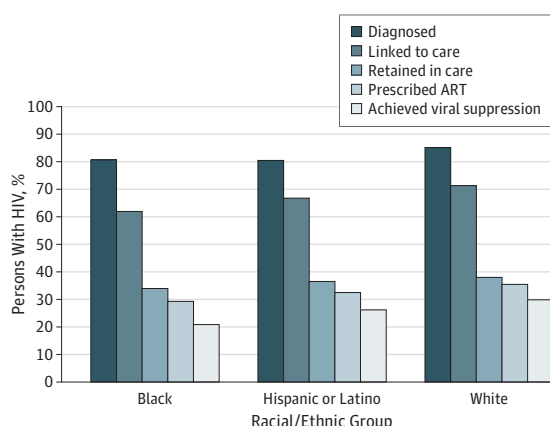
stand how racism, stigma, and homophobia can also affect access to and willingness to stay in care.<sup>19</sup> For example, discomfort with and distrust of the health care system and health care providers and feeling stigmatized and unsupported by family and community because of sexual orientation can keep people from care.

Factors that likely contribute to the disparities in HIV diagnosis and care for younger people include lower rates of HIV testing,<sup>20</sup> a reduced sense of urgency about the need for care among those who are HIV-positive, and less adherence to an ART regimen.<sup>21</sup> Persons who feel healthy may be less motivated to stay in care, which may be a barrier to retention among younger people and those who are in the earlier stages of infection. In addition, young people likely had higher CD4 T-lymphocyte counts and may not have been offered ART because treatment guidelines at the time reflected in our data recommended ART according to severity of disease.<sup>22</sup> Many older persons with HIV, on the other hand, are alive because they have received care and treatment.

Effective interventions for linkage to and retention in care should address barriers to accessing care, including services specifically intended to mitigate individual barriers, such as drug use, lack of housing assistance, limited transportation, and absence of child care. In addition, the patient-provider relationship is an important determinant of one's use of health care resources, including effective communication, time to address individual needs, prompt scheduling of appointments, and support through case managers.<sup>8</sup> Increased coordination between testing and care service providers is needed to ensure that persons diagnosed as having HIV are promptly linked to care and receive follow-up services to remain in care.<sup>19</sup> Although some promising approaches using outreach and case management to improve retention in care have been implemented,<sup>23-26</sup> additional research is needed on interventions for retention in care.

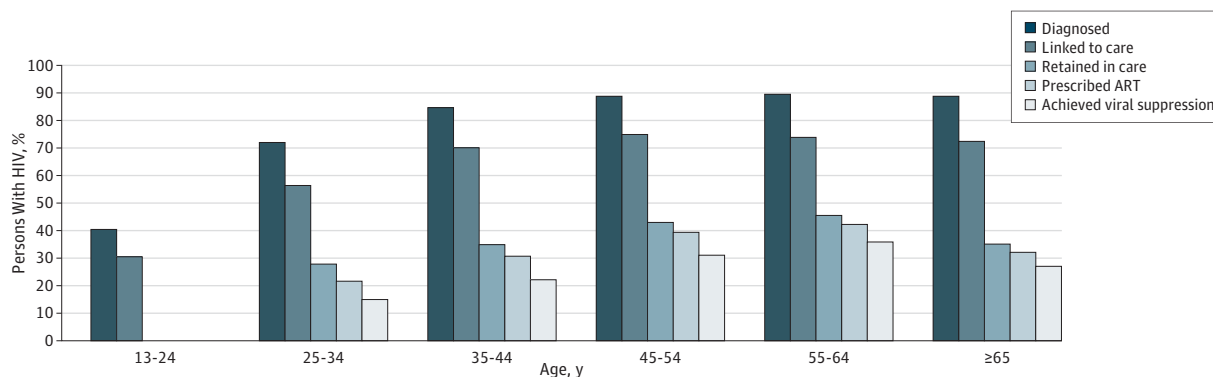
The need for services is likely to increase not only with improved linkage and retention in care but also with the recommendations of revised treatment guidelines released in 2012, which call for offering ART to all persons with HIV regardless of their stage of disease.<sup>27,28</sup> Achieving full coverage would re-

**Figure 1. Percentage of Persons With Human Immunodeficiency Virus (HIV) Infection**



Percentages are shown for US individuals engaged in selected stages of the continuum of care by race/ethnicity. ART indicates antiretroviral therapy.

**Figure 2. Percentage of Persons With Human Immunodeficiency Virus (HIV) Infection**



Percentages are shown for US individuals engaged in selected stages of the continuum of care by age. ART indicates antiretroviral therapy.



Table 2. Persons Living With HIV in 2009 Who Achieved Each Step in the Continuum of Engagement in Care by Selected Characteristics, United States

Characteristic	Continuum of Care, %			
	Living With Diagnosed HIV <sup>a</sup>	Retained in Care Among Those Living With Diagnosed HIV	Prescribed ART Among Those Retained in Care	Achieved Suppressed Viral Load Among Those Prescribed ART
Total	82	45	89	78
Sex				
Male	81	43	90	80
Female	85	49	86	73
Race/ethnicity				
Black	81	42	86	71
Hispanic or Latino	80	45	89	80
White	85	45	92	84
Transmission category				
MSM contact	79	46	90	82
Injection drug use				
Male	90	36	92	75
Female	91	48	89	71
MSM contact and injection drug use	91	43	89	75
Heterosexual contact				
Male	76	38	91	74
Female	82	48	85	74
Age group, y				
13-24	41			
25-34	72	39	78	70
35-44	85	41	88	73
45-54	89	49	91	79
55-64	89	51	92	86
≥65	89	40	92	84

Abbreviation: ART, antiretroviral therapy; HIV, human immunodeficiency virus; MSM, male-to-male sexual contact.

<sup>a</sup> Percentages are from Table 1.

quire scaling up of services to the more than 560 000 persons living with diagnosed HIV who are not receiving regular ART.

The National HIV/AIDS Strategy<sup>29</sup> sets benchmarks for increasing the percentage of persons with HIV infection who are aware of their infection, are linked to and retained in care, and achieve viral suppression. Our analyses indicate a need for improvement overall and in particular to reduce disparities in the awareness of HIV infection and receipt of effective care for blacks and Hispanics or Latinos. Ensuring high coverage in each step of the continuum for those who have MSM contact is also crucial to address HIV in the United States because those with MSM contact were the only risk group with increases in HIV incidence in recent years,<sup>9</sup> and our findings that only 36% of those with MSM contact living with HIV were retained in care means that many may not be receiving adequate counseling for risk behaviors and treatment to prevent the transmission of HIV.

Our analyses are subject to several limitations. First, our estimation of linkage to care was based on data from only 14 areas, and these data may have been subject to reporting delays. However, the percentage of individuals linked to care among those diagnosed was slightly higher (80%) compared with an earlier estimate based on the literature (77%).<sup>1</sup> Also, we applied the percentage linked to care based on persons diagnosed in a recent year who had been linked to care within 3

months after diagnosis to the total population with HIV. We did not have data to determine whether all prevalent cases had been linked to care within 3 months of diagnosis or at any time. Second, retention in care may be underestimated when based on MMP data because only persons who had a medical care visit from January through April were sampled. Persons who had medical visits only in the last 8 months of the year would not have been considered to be in care. Third, a higher percentage of youth younger than 18 years may be in care compared with young adults 18 years or older.<sup>30</sup> Fourth, numbers were too small for other race groups to be included. Our results need to be interpreted in light of the treatment guidelines relevant at the time, which called for ART prescription according to stage of disease and other relevant factors<sup>22,31</sup> rather than the universal offering of treatment recommended in 2012.<sup>27,28</sup> Statistical differences were assessed only for the final steps in the continuum (ie, care, prescription of ART, and viral suppression); however, the differences in persons diagnosed as having HIV have been previously published.<sup>2</sup> Finally, denominator and numerator data were not available to examine differences in the continuum based on geographic region of the United States. With improvements in laboratory reporting of HIV-related tests, especially CD4 levels and viral load test results, future analyses will allow examination of the continuum for individual states and by region.

In summary, a large percentage of persons with HIV did not have a suppressed viral load. In addition, persons younger than 45 years were less likely to be aware of their infection or have a suppressed viral load. Improvements are needed at each step of the process, including expanding HIV testing to identify the more than 200 000 Americans living with HIV who do not know they are infected and to address disparities in care and treatment. Increasing the percentage of young persons diagnosed and receiving continuous care

is critical to addressing HIV in the United States. Ensuring that people stay in care and receive treatment will increase the proportion of HIV-infected individuals who achieve and maintain a suppressed viral load. Individuals, health care providers, health departments, and government agencies must all work together to increase the numbers of people living with HIV who are aware of their status, linked to and retained in care, receiving treatment, and adherent to treatment.

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**Acquisition of data:** Hall, Skarbinski.

**Analysis and interpretation of data:** Hall, Frazier, Rhodes, Furlow-Parmley, Tang, Gray, Cohen, Mermin, Skarbinski.

**Drafting of the manuscript:** Hall, Mermin, Skarbinski.

**Critical revision of the manuscript for important intellectual content:** All authors.

**Statistical analysis:** Hall, Frazier, Rhodes, Furlow-Parmley, Tang, Skarbinski.

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## REFERENCES

- Centers for Disease Control and Prevention. Vital signs: HIV prevention through care and treatment—United States. *MMWR Morb Mortal Wkly Rep*. 2011;60(47):1618-1623.
- Centers for Disease Control and Prevention. Monitoring selected national HIV prevention and care objectives by using HIV surveillance data: United States and 6 US dependent areas—2010. HIV Surveillance Supplemental Report. 2012;17(3, part A). Published June 2012. <http://www.cdc.gov/hiv/topics/surveillance/resources/reports/>. Accessed August 8, 2012.
- Hall HI, Holtgrave DR, Maulsby C. HIV transmission rates from persons living with HIV who are aware and unaware of their infection. *AIDS*. 2012;26(7):893-896.
- Giordano TP, Gifford AL, White AC Jr, et al. Retention in care: a challenge to survival with HIV infection. *Clin Infect Dis*. 2007;44(11):1493-1499.
- Mugavero MJ, Davila JA, Nevin CR, Giordano TP. From access to engagement: measuring retention in outpatient HIV clinical care. *AIDS Patient Care STDS*. 2010;24(10):607-613.
- Mugavero MJ, Lin H-Y, Willig JH, et al. Missed visits and mortality among patients establishing initial outpatient HIV treatment. *Clin Infect Dis*. 2009;48(2):248-256.
- Ulett KB, Willig JH, Lin HY, et al. The therapeutic implications of timely linkage and early retention in HIV care. *AIDS Patient Care STDS*. 2009;23(1):41-49.
- Aberg JA, Kaplan JE, Libman H, et al; HIV Medicine Association of the Infectious Diseases Society of America. Primary care guidelines for the management of persons infected with human immunodeficiency virus: 2009 update by the HIV Medicine Association of the Infectious Diseases Society of America. *Clin Infect Dis*. 2009;49(5):651-681.
- Prejean J, Song R, Hernandez A, et al; HIV Incidence Surveillance Group. Estimated HIV incidence in the United States, 2006-2009. *PLoS One*. 2011;6(8):e17502. doi:10.1371/journal.pone.0017502.
- Centers for Disease Control and Prevention. Diagnoses of HIV infection and AIDS in the United States and dependent areas, 2010. HIV Surveillance Report, vol. 22. Atlanta, GA: US Dept of Health and Human Services, CDC; 2012. <http://www.cdc.gov/hiv/surveillance/resources/reports/2010report/index.htm>. Accessed May 25, 2012.
- Hall HI, Song R, Rhodes P, et al; HIV Incidence Surveillance Group. Estimation of HIV incidence in the United States. *JAMA*. 2008;300(5):520-529.
- McNaghten AD, Wolfe MI, Onorato I, et al. Improving the representativeness of behavioral and clinical surveillance for persons with HIV in the United States: the rationale for developing a population-based approach. *PLoS One*. 2007;2(6):e550. doi:10.1371/journal.pone.0000550.
- Blair JM, McNaghten AD, Frazier EL, Skarbinski J, Huang P, Heffelfinger JD. Clinical and behavioral characteristics of adults receiving medical care for HIV infection: Medical Monitoring Project, United States, 2007. *MMWR Surveill Summ*. 2011;60(11):1-20.
- Frankel MR, McNaghten AD, Shapiro MF, et al. A probability sample for monitoring the HIV-infected population in care in the U.S. and in selected states. *Open AIDS J*. 2012;6:67-76. doi:10.2174/1874613601206010067.
- Oehlert GW. A note on the delta method. *Am Stat*. 1992;46(1):27-29.
- DeNavas-Walt C, Proctor BD, Smith JC. *US Census Bureau, Current Population Reports, P60-243: Income, Poverty, and Health Insurance Coverage in the United States: 2011*. Washington, DC: US Census Bureau; 2012.
- Horstmann E, Brown J, Islam F, Buck J, Agins BD. Retaining HIV-infected patients in care: where are we? where do we go from here? *Clin Infect Dis*. 2010;50(5):752-761.
- Wohl AR, Galvan FH, Myers HF, et al. Do social support, stress, disclosure and stigma influence retention in HIV care for Latino and African American men who have sex with men and women? *AIDS Behav*. 2011;15(6):1098-1110.
- McNairy ML, El-Sadr WM. The HIV care continuum: no partial credit given. *AIDS*. 2012;26(14):1735-1738.
- Centers for Disease Control and Prevention. Vital signs: HIV infection, testing, and risk behaviors among youth—United States. *MMWR Morb Mortal Wkly Rep*. 2012;61(47):971-976.
- Rudy BJ, Murphy DA, Harris DR, Muenz L, Ellen J; Adolescent Trials Network for HIV/AIDS Interventions. Patient-related risks for nonadherence to antiretroviral therapy among HIV-infected youth in the United States: a study of prevalence and interactions. *AIDS Patient Care STDS*. 2009;23(3):185-194.
- Panel on Antiretroviral Guidelines for Adults and Adolescents. Guidelines for the use of antiretroviral agents in HIV-1-infected adults and adolescents. Dept of Health and Human Services. January 10, 2011:1-166. <http://www.aidsinfo.nih.gov/ContentFiles/AdultandAdolescentGL.pdf>. Accessed April 8, 2011.
- Thompson MA, Mugavero MJ, Amico KR, et al. Guidelines for improving entry into and retention in care and antiretroviral adherence for persons with HIV: evidence-based recommendations from an International Association of Physicians in AIDS Care panel. *Ann Intern Med*. 2012;156(11):817-833; W-284&#8211. doi:10.1059/0003-4819-156-11-201206050-00419.
- Gardner LI, Metsch LR, Anderson-Mahoney P, et al; Antiretroviral Treatment and Access Study (ARTAS) Study Group. Efficacy of a brief case management intervention to link recently diagnosed HIV-infected persons to care. *AIDS*. 2005;19(4):423-431.
- Bradford JB. The promise of outreach for engaging and retaining out-of-care persons in HIV medical care. *AIDS Patient Care STDS*. 2007;21(suppl 1):S85-S91.

26. Wohl AR, Garland WH, Wu J, et al. A youth-focused case management intervention to engage and retain young gay men of color in HIV care. *AIDS Care*. 2011;23(8):988-997.

27. Thompson MA, Aberg JA, Hoy JF, et al. Antiretroviral treatment of adult HIV infection: 2012 recommendations of the International Antiviral Society–USA panel. *JAMA*. 2012;308(4):387-402.

28. Panel on Antiretroviral Guidelines for Adults and Adolescents. Guidelines for the use of

antiretroviral agents in HIV-1-infected adults and adolescents. Dept of Health and Human Services. March 27, 2012;1-166. <http://www.aidsinfo.nih.gov/contentfiles/lvguidelines/adultandadolescentgl.pdf>. Accessed August 19, 2012.

29. Office of National AIDS Policy. National HIV/AIDS Strategy. July 2010. <http://www.whitehouse.gov/administration/eop/nap/nhas/>. Accessed November 6, 2012.

30. Hall HI, Gray KM, Tang T, Li J, Shouse L, Mermin J. Retention in care of adults and adolescents living

with HIV in 13 US areas. *J Acquir Immune Defic Syndr*. 2012;60(1):77-82.

31. Thompson MA, Aberg JA, Cahn P, et al; International AIDS Society–USA. Antiretroviral treatment of adult HIV infection: 2010 recommendations of the International AIDS Society–USA panel. *JAMA*. 2010;304(3):321-333.

## Invited Commentary

# Overcoming the Human Immunodeficiency Virus Obstacle Course

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Approximately 50 000 new human immunodeficiency virus (HIV) infections develop in the United States each year.<sup>1</sup> How many of these people know of their HIV infection? How many are engaged in HIV care? How many are successfully treated with antiretroviral therapy (ART)? Surprisingly, until very recently, the answers to these simple questions regarding HIV care were unknown.

In 2011, the HIV field was shocked to learn that only about a quarter of individuals living with HIV were successfully receiving HIV treatment.<sup>2</sup> The steps to effective treatment, often referred to as the *HIV care continuum* or *cascade*—testing, linkage to care, retention in care, ART initiation, and achievement of an undetectable viral load—often operated more like an obstacle course than a smoothly paved road. Hurdles to successful HIV care include factors that are structural (eg, poverty, lack of health insurance), psychosocial (eg, stigma, substance use, mental illness), and clinic based (eg, the patient-provider relationship).<sup>3</sup>



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The sobering numbers of those missing out on effective treatment because they did not know they were infected and those who knew their status but did not seek care spurred collaboration between the HIV treatment and prevention movements, 2 areas with different funding streams that often operated independently of one another. This collaboration was further catalyzed by the recognition that effective HIV treatment is effective HIV prevention, because treatment decreases the likelihood of an infected person transmitting the virus.

Efforts to define and intervene on the steps of HIV care have led to reallocation of funding and increased coordination between federal and local agencies, an explicit aim of the National HIV/AIDS Strategy.<sup>4</sup> Indeed, the proportion of persons making it through each step of the path to successful treatment creates a baseline against which to measure the effect of policy changes, such as shifts in HIV treatment guidelines, and structural reforms, such as the Affordable Care Act.<sup>5</sup>

Hall et al<sup>6</sup> use data from the Centers for Disease Control and Prevention National HIV Surveillance System and the

Medical Monitoring Project to estimate the percentage of persons living with HIV in the United States at each step of HIV care. More than 850 000 individuals have a detectable viral load. Blacks and Hispanics are less likely to be aware of their infection, and youth in particular are significantly less likely to know their status and receive successful HIV treatment. Eliminating these racial, ethnic, and age disparities requires addressing intersecting barriers to care that include health beliefs, trust in providers, and stigma related to HIV, sexual identity, and drug use.

Where do we go from here? The HIV cascade represents care as a linear phenomenon, yet individuals frequently move in and out of care.<sup>7</sup> The cascade framework does not include estimates of mortality, making it key to understand the fraction of deaths attributable to failure at each step. In addition, cascade-related analyses tend to provide cross-sectional estimates and correlates. More work is needed to understand how an individual moves through the steps of the cascade over time and how each step may influence subsequent steps.<sup>8</sup>

Indeed, the cascade in its current iteration does not account for patient experiences. The benchmarks that are meaningful to patients in their successful movement through the steps of HIV testing and care are not necessarily the ones outlined by the cascade. In a similar way, definitions of engagement in care must expand to include more patient-centered metrics. Keeping appointments and achieving virologic suppression are necessary, but they are not sufficient. As implied by the meaning of the word *engaged*—“to attract and hold fast”—being truly engaged in care involves psychosocial constructs that must be clarified, measured, and promoted.

Despite these limitations, there is a quiet power in the simplicity of the cascade. The cascade expresses core tenets of HIV diagnosis, treatment, and prevention. Amidst a chaotic and fragmented health care system, the points of reference offered by the cascade command attention because they are directly relevant to the real world, not just to public health officials and researchers. Defining the cascade at local, national, and global levels can catalyze systematic improvements that result in fewer HIV-infected persons being unaware of their illness and more persons receiving successful treatment. These