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# Differences in Selected HIV Care Continuum Outcomes Among People Residing in Rural, Urban, and Metropolitan Areas – 28 United States Jurisdictions

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**Keywords:** HIV, rural, metropolitan, care continuum

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### Abstract

**Purpose.** The HIV care continuum is used to monitor success in HIV diagnosis and treatment among persons living with HIV in the United States. Significant differences exist along the HIV care continuum between subpopulations of people living with HIV; however, differences that may exist between residents of rural and non-rural areas have not been reported.

**Methods.** We analyzed the Centers for Disease Control and Prevention's National HIV Surveillance System data on adults and adolescents ( $\geq 13$  years) with HIV diagnosed in 28 jurisdictions with complete reporting of HIV-related lab results. Lab data were used to assess linkage to care ( $\geq 1$  CD4 or viral load test  $\leq 3$  months of diagnosis), retention in care ( $\geq 2$  CD4 and/or viral load tests  $\geq 3$  months apart) and viral suppression (viral load  $< 200$  copies/mL) among persons living with HIV. Residence at diagnosis was grouped into rural ( $< 50,000$  population), urban (50,000-499,999 population), and metropolitan ( $\geq 500,000$  population) categories for statistical comparison. Prevalence ratios and 95% confidence intervals were calculated to assess significant differences in linkage, retention, and viral suppression.

**Findings.** Although greater linkage to care was found for rural residents (84.3%) compared to urban residents (83.3%) and metropolitan residents (81.9%), significantly lower levels of retention in care and viral suppression were found for residents of rural (46.2% and 50.0%, respectively) and urban (50.2% and 47.2%) areas compared to residents of metropolitan areas (54.5% and 50.8%).

**Conclusions.** Interventions are needed to increase retention in care and viral suppression among people with HIV in non-metropolitan areas of the United States.

**Key words:** care continuum, HIV, metropolitan, rural

People living in rural areas of the United States (US) and its territories often have less access to resources and services for the management of chronic illness than people living in non-rural areas.

People living with HIV (PLWH) in rural areas potentially have additional barriers including: isolating stigmas (related to one or more factors including having HIV, sexual orientation, substance use, poverty, race/ethnicity), increased risk of breaks in confidentiality, and fear of being victimized or ostracized within the rural community for disclosure of a stigmatized characteristic.<sup>1,2</sup>

The HIV care continuum has been used since 2011<sup>3</sup> to measure progress towards best care of HIV in the US. The continuum allows for evaluation and comparison of the percentages of persons living with diagnosed HIV, linked to HIV care, retained in care, prescribed combination antiretroviral therapy, and who have achieved viral suppression as a measure of success in diagnosis, care and treatment in particular regions of the country. Because of multiple health inequities (that may be associated with race/ethnicity, sex, sexual orientation, age, socioeconomic status, residency status), there are significant differences in some care continuum outcomes between subpopulations of PLWH in the US.<sup>4-6</sup>

Rural residents may be at a disadvantage for accessing and receiving HIV-related services. Although the prevalence of HIV infection tends to positively correlate to population size, with a higher prevalence rate in metropolitan areas than rural areas, in the Southeast, the prevalence in rural areas can be similar to or greater than non-rural areas.<sup>7</sup> For example, in South Carolina prevalence of HIV infection is higher among rural residents (320/100,000) than the state collectively (317/100,000).<sup>8</sup> HIV testing among rural residents has been found to be significantly lower than among urban residents. In one national study, 43.6% of urban residents reported ever having been tested for HIV while only 32.2% of rural residents reported ever having been tested.<sup>9</sup> In the most rural regions of the US, individuals at greatest risk of acquiring HIV, based on demographics and self-reported risk factors, were found to be significantly less likely to have been tested in the last year. For residents of rural areas, only 7.3% have been HIV tested within the past year, while 13.5% of urban residents have been tested.<sup>9</sup> Lack of HIV

testing among high-risk rural residents may be contributing to disparities in late diagnoses among this population. In 2 studies comparing rural and urban residents in the Southeast, rural residents were significantly more likely to have a “late HIV diagnosis” (ie, HIV infection classified as stage 3 [AIDS]  $\leq 3$  months or  $< 1$  year of initial HIV diagnosis).<sup>10,11</sup>

In terms of linkage to care, retention in care, and viral suppression, the picture is less clear. In a study of New York State residents with diagnosed HIV infection, those residing outside of New York City were more likely to be linked to care within 3 months of initial diagnosis compared to those in New York City<sup>4</sup>; however, this study did not differentiate between people residing in rural and urban communities. While linkage and retention has been identified as difficult in rural communities for various reasons (primarily transportation, provider stigma and discrimination, and confidentiality concerns),<sup>12</sup> some barriers to care have been identified as being greater for urban women compared to rural women (primarily regarding stigma and fatalism).<sup>13</sup>

A comparison of HIV care continuum outcomes for PLWH residing in metropolitan areas to those residing in rural areas has not been reported for the US. This analysis was done to identify if there were any significant differences in linkage to care, retention in care, and viral suppression among PLWH ( $\geq 13$  years) residing in rural and non-rural jurisdictions in the US.

## Methods

We analyzed data from the Centers for Disease Control and Prevention’s (CDC) National HIV Surveillance System (NHSS) on adults and adolescents ( $\geq 13$  years) with HIV diagnosed in 28 US jurisdictions with complete reporting of HIV-related laboratory test results during 2012-2014. Our aim was to determine linkage to care, retention in care, and viral suppression among residents of rural and non-rural areas.<sup>14</sup> The 28 jurisdictions included Alabama, Alaska, Arkansas, California, the District of Columbia, Hawaii, Illinois, Indiana, Iowa, Louisiana, Maine, Maryland, Michigan, Missouri, Nebraska, New Hampshire, New

York, North Dakota, Oregon, South Carolina, South Dakota, Tennessee, Texas, Utah, Virginia, Washington, West Virginia, and Wisconsin. Linkage to care was defined as  $\geq 1$  CD4 or viral load (VL) test result within 3 months of diagnosis. For this study, linkage to care was assessed for people with HIV diagnosed in 2013. Retention in HIV medical care was defined as  $\geq 2$  CD4 and/or VL test results at least 3 months apart during 2012 and viral suppression as the most recent VL test result of  $< 200$  copies per milliliter in 2012 and was assessed for persons with HIV infection diagnosed prior to 2011 who were still alive at year-end 2012. Data were reported to the CDC through December 2014.

Although the definition of “rural” is not uniform across all US government programs,<sup>15,16,17</sup> “rural” is commonly defined by the US Census Bureau<sup>18</sup> as being a territory that is populated with  $< 50,000$  people. For this analysis, a person’s residence at HIV diagnosis was categorized as “rural” ( $< 50,000$  population), “urban” (50,000-499,999 population), or “metropolitan” ( $\geq 500,000$  population). Geographic category assignments were based on the 2010 metropolitan and micropolitan statistical area delineations from the US Office of Management and Budget.<sup>19,20</sup> While the persons included in the analyses represent a census of persons in the jurisdictions included in the analyses, the jurisdictions included could be considered a convenience sample for the US. Therefore, prevalence ratios (PR) and 95% confidence intervals (CIs) were calculated to assess significant differences in percentages of persons linked and retained in care, and who achieved viral suppression among residents of rural and urban areas compared to residents of metropolitan areas, the referent group. The analyses did not control for potential confounding variables. PR and 95% CIs were calculated to determine differences in percentages by selected demographic characteristics (sex, age, race/ethnicity, and transmission category) for persons with HIV diagnosed in 2013 and PLWH at year-end 2012. Comparisons were made for persons with diagnosed HIV in metropolitan areas against persons with diagnosed HIV in urban or rural areas.

## Results

Among 24,413 persons who received a diagnosis of HIV infection in 2013 (Table 1), 81.9% of persons (n=20,187) residing in metropolitan areas were linked to care within 3 months after diagnosis; 83.3% (PR=1.02; CI: 0.99-1.03) of persons (n=3,248) were linked in urban areas, and 84.3% (PR=1.03; CI: 0.99-1.06) of persons (n=877) in rural areas (Figure 1). The demographic distribution varied slightly across the geographic categories for persons with HIV diagnosed in 2013. The percentage of males ranged from 78.8% in rural areas to 81.9% metropolitan areas (Table 1). By age group, the largest group for each geographic category was persons aged 25-34 years with percentages ranging from 28.4% in urban areas to 31.8% in metropolitan areas. By race/ethnicity, the largest group for each geographic category was blacks/African Americans with percentages ranging from 41.4% in both urban and rural areas to 43.9% in metropolitan areas. Males with infection attributed to male-to-male sexual contact accounted for the largest percentage of persons with diagnosed HIV by transmission category, with percentages ranging from 57.2% in rural areas to 69.1% in metropolitan areas. Using prevalence ratios, persons in rural areas compared to persons in metropolitan areas were found more likely be female (PR=1.17; CI: 1.03-1.34) and white (PR=1.45; CI: 1.32-1.59), and less likely to have acquired HIV as a result of male-to-male sexual contact only (PR=0.83; CI: 0.78-0.88).

Among 530,250 PLWH diagnosed through year-end 2011 (Table 2), 54.5% of persons (n=447,749) residing in metropolitan areas at time of HIV diagnosis were retained in HIV medical care during 2012, 50.2% of persons (n=62,486) in urban areas (PR=0.92; CI: 0.91-0.93) and 50.0% of persons (n=15,581) in rural areas (PR=0.92; CI=0.90, 0.93) (Figure 2). Among the same population used to measure retention, viral suppression was achieved in 2012 by 50.8% among those residing in metropolitan areas at the time of HIV diagnosis, 47.2% (PR=0.93; CI: 0.92-0.94) in urban areas, and 46.2% (PR = 0.91; CI: 0.90-0.93) of those in rural areas (Figure 2). There was some variation in the demographic distribution across the geographic categories for persons living with diagnosed HIV at year-



end 2012. The percentage of males ranged from 72.1% in rural areas to 77.5% in urban areas (Table 2). By age group, the largest group for each geographic category was persons aged 45-54 years with percentages ranging from 35.1% in rural areas to 35.5% in urban areas. By race/ethnicity, blacks/African Americans accounted for the largest group in metropolitan (40.6%) and rural (45.2%) areas. Whites accounted for the largest racial/ethnic group (42.7%) in urban areas. Males with infection attributed to male-to-male sexual contact accounted for the largest percentage of persons with diagnosed HIV by transmission category, with percentages ranging from 41.2% in rural areas to 55.1% in metropolitan areas. Persons living with diagnosed HIV in rural areas at the end of 2012 were more likely than persons in metropolitan areas to be female (PR=1.21; CI: 1.18-1.24), white (PR=1.26; CI: 1.23-1.28) or black/African American (PR=1.11; CI: 1.09-1.13), and less likely to be Hispanic/Latino (PR=0.52; CI: 0.50-0.54) or to have acquired HIV infection through male-to-male sexual contact (PR=0.75; CI: 0.73-0.76). Age distributions were similar across the geographic categories; however, rural persons were more likely to be 35-44 years old (PR=1.07; CI: 1.04-1.10), and slightly less likely to be age 55 years or older (PR=0.91; CI: 0.88-0.94).

## Discussion

In all population categories, the majority of people who received a diagnosis of HIV in 2013 were promptly linked to care. The percentage retained in care and virally suppressed was significantly lower among PLWH who were initially diagnosed in rural areas. Percentage distributions were similar for linkage to care, retention in care, and viral suppression between persons in urban and rural areas. Some differences in percentages of persons with HIV diagnosed in 2013 and PLWH by year-end 2012 (and initially diagnosed by year-end of 2011) by demographic group were found when comparing persons in rural and metropolitan areas and may have contributed to the findings of this study. Another limitation of this study is whether or not there were significant differences in HIV morbidity at the time

of diagnosis between the rural, urban, and metropolitan populations. Some studies<sup>10,11</sup> have indicated that living in a rural area is associated with being older, having a more advanced stage classification at initial diagnosis, and being diagnosed with AIDS sooner following HIV diagnosis. PLWH in rural areas may link to care more readily as a result of symptoms or being older, but then subsequently drop out of care after linkage. Availability of services (pharmacy access, antiretroviral medications, and mental health services) for PLWH vary from one rural community to another and geographical barriers for PLWH in these areas may result from several factors including time/distance to nearest medical facility, availability of providers, environmental barriers to accessing care (ie, poor roads), lack of communication services, stigma, and availability of HIV care support.<sup>12,21,22</sup>

Retention in care and viral suppression was assessed for the prevalent (all persons living with diagnosed HIV) populations of each geographic category to highlight the gaps that may exist in connecting persons to sustained, quality care. Theoretically, 100% of persons with diagnosed HIV should be linked to care, retained in care, and virally suppressed. However, the US HIV care continuum has resembled more of a cascade since first described in 2011.<sup>3</sup> To guide local, state, and national efforts to increase the percentages of people engaged in the continuum from HIV diagnosis to viral suppression, the National HIV/AIDS Strategy<sup>23</sup> emphasizes prevention and intervention service provision at clinics, community centers, and nontraditional settings (eg, mental health centers). These services include HIV testing, as well as linkage to and retention in long-term quality care that seeks to sustain viral suppression through promotion of adherence after timely initiation of antiretroviral therapy and provision of coordinated care for therapy-associated complications, other coinfections, substance addiction, and mental health issues.<sup>24,25</sup> HIV prevention and intervention service delivery should be expanded to vulnerable populations in rural health settings; however, local jurisdictions should consider the impact of migration after initial diagnosis among people diagnosed in nonmetropolitan areas in program planning. Previous studies<sup>26-28</sup> have found persons from rural areas may migrate to more

populated municipalities after HIV diagnosis for fear of stigma, confidentiality issues, and availability of appropriate HIV-related medical care. Future studies should follow and assess retention in care in larger geographic areas among persons who are initially linked to care in rural areas.

This analysis was subject to several additional limitations. Data were available from 28 US jurisdictions with complete reporting of HIV-related lab data to the CDC; these jurisdictions may not be representative of all people with diagnosed HIV infection in the US during the study time period, and these jurisdictions were not evaluated for differences in resource availability (ie, equal availability of HIV testing and HIV care services). The residence used to designate cases into the 3 population categories for PLWH was based on their residence at the time of initial HIV diagnosis. Retention in care and viral suppression among people who have moved from a rural region to a non-rural region, or from a metropolitan area to a non-metropolitan area, may not be the same as that associated with the residence at diagnosis. Since CD4 and VL test results reported to HIV surveillance programs were relied on to monitor linkage and retention in care and viral suppression, not having these tests done or reported limits the inclusion criteria for linkage and retention in care. Some people with HIV may have care visits that do not result in a CD4 or VL lab test. Data on CD4 and VL test results during the follow-up period may be missing for people who moved to a jurisdiction after HIV diagnosis that did not report VL test results to the NHSS.

Lower levels of retention in care and viral suppression were observed among PLWH who resided in rural areas at the time of diagnosis. The targeted goals of the US National HIV/AIDS Strategy<sup>23</sup> by 2020 include: 85% of all newly diagnosed HIV-infected persons will be linked to care within one month of diagnosis, 90% of all identified PLWH will be retained in care, and 80% of all PLWH will be virally suppressed. Establishment of solid prevention, intervention, care, and treatment infrastructures are needed to enhance care and treatment for PLWH in all geographic areas of the US, including people residing in rural areas.



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**Table 1. Diagnoses of HIV Infection Among Adults and Adolescents, by Geographic Population Category and Selected Characteristics, 27 States and the District of Columbia**

	Metropolitan (pop≥500,000)		Urban (pop 50,000-499,999)		Rural (pop 10,000-49,000)		Unknown		Total	
	No.	%	No.	%	No.	%	No.	%	No.	%
<b>Sex</b>										
Male	16,535	81.9	2,607	80.3	691	78.8	86	85.1	19,919	81.6
Female	3,652	18.1	641	19.7	186	21.2	15	14.9	4,494	18.4
<b>Age at diagnosis</b>										
13-24	4,466	22.1	772	23.8	168	19.2	13	12.9	5,419	22.2
25-34	6,420	31.8	905	27.9	249	28.4	27	26.7	7,601	31.1
35-44	4,096	20.3	660	20.3	196	22.3	17	16.8	4,969	20.4
45-54	3,378	16.7	562	17.3	169	19.3	24	23.8	4,133	16.9
≥55	1,827	9.1	349	10.7	95	10.8	20	19.8	2,291	9.4
<b>Race/ethnicity</b>										
American Indian/Alaska Native	30	0.1	15	0.5	13	1.5	0	0	58	0.2
Asian	585	2.9	54	1.7	4	0.5	3	3	646	2.6
Black/African American	8,853	43.9	1,344	41.4	363	41.4	45	44.6	10,605	43.4
Hispanic/Latino <sup>a</sup>	5,091	25.2	504	15.5	163	18.6	21	20.8	5,779	23.7
Native Hawaiian/Other Pacific Islander	36	0.2	11	0.3	0	0	0	0	47	0.2
White	4,952	24.5	1,227	37.8	311	35.5	28	27.7	6,518	26.7
Multiple races	640	3.2	93	2.9	23	2.6	4	4	760	3.1
<b>Transmission category<sup>b</sup></b>										
Male-to-male sexual contact	13,951	69.1	2,084	64.2	502	57.2	53	52.4	16,590	68
Injection drug use	1,076	5.3	240	7.4	77	8.8	16	16.1	1,409	5.8
Male-to-male sexual contact and injection drug use	584	2.9	114	3.5	36	4.1	4	4	739	3
Heterosexual contact <sup>c</sup>	4,511	22.3	801	24.7	261	29.7	28	27.5	5,600	22.9
Other <sup>d</sup>	65	0.3	9	0.3	1	0.1	0	0	75	0.3
<b>Total</b>	20,187	100	3,248	100	877	100	101	100	24,413	100

Note. Data include persons with diagnosed HIV infection regardless of stage of disease at diagnosis.


<sup>a</sup>Hispanics/Latinos can be of any race.

<sup>b</sup>Data have been statistically adjusted to account for missing transmission category.

<sup>c</sup>Heterosexual contact with a person known to have, or to be at high risk for, HIV infection.

<sup>d</sup>Includes persons whose infection was attributed to hemophilia, blood transfusion, or perinatal exposure or whose risk factor was not reported or not identified.


Note. Linkage to care was defined as having  $\geq 1$  CD4 or VL test  $\leq 3$  months after HIV diagnosis.

 **2. Persons With HIV Infection Diagnosed by Year-End 2011 and Alive at Year-End of 2012, by Geographic Population Category and Selected Characteristics, 2012, 27 States and The District Of Columbia**

	Metropolitan (pop $\geq 500,000$ )		Urban (pop 50,000-499,999)		Rural (pop 10,000-49,000)		Unknown		Total	
	No.	%	No.	%	No.	%	No.	%	No.	%
<b>Sex</b>										
Male	344,222	76.9	48,419	77.5	11,235	72.1	3,607	81.3	407,483	76.8
Female	103,527	23.1	14,067	22.5	4,346	27.9	827	18.7	122,767	23.2
<b>Age at end of 2011</b>										
13-24	19,490	4.4	2,846	4.6	695	4.5	145	3.3	23,176	4.4
25-34	62,556	14	9,235	14.8	2,235	14.3	354	8	74,380	14
35-44	110,052	24.6	15,965	25.5	4,109	26.4	953	21.5	131,079	24.7
45-54	158,328	35.4	22,156	35.5	5,475	35.1	1,916	43.2	187,875	35.4
$\geq 55$	97,323	21.7	12,284	19.7	3,067	19.7	1,066	24	113,740	21.5

## Rural HIV Care Continuum Differences

<b>Race/ethnicity</b>										
American Indian/Alaska Native	742	0.2	278	0.4	140	0.9	15	0.3	1,175	0.2
Asian	7,207	1.6	535	0.9	40	0.3	45	1	7,827	1.5
Black/African American	182,773	40.8	23,682	37.9	7,036	45.2	1,666	37.6	215,157	40.6
Hispanic/Latino <sup>a</sup>	104,327	23.3	8,967	14.4	1,885	12.1	807	18.2	115,986	21.9
Native Hawaiian/Other Pacific Islander	505	0.1	116	0.2	1	0	4	0.1	626	0.1
White	136,066	30.4	26,700	42.7	5,955	38.2	1,724	38.9	170,445	32.1
Multiple races	16,129	3.6	2,208	3.5	524	3.4	173	3.9	19,034	3.6
<b>Transmission category<sup>b</sup></b>										
Male-to-male sexual contact	246,737	55.1	30,337	48.5	6,420	41.2	2,355	53.1	285,848	53.9
Injection drug use	66,159	14.8	10,955	17.5	3,020	19.4	823	18.6	80,957	15.3
Male-to-male sexual contact and injection drug use	25,744	5.7	5,120	8.2	1,135	7.3	351	7.9	32,349	6.1
Heterosexual contact <sup>c</sup>	102,118	22.8	15,130	24.2	4,718	30.3	790	17.8	122,755	23.2
Other <sup>d</sup>	6,992	1.6	945	1.5	288	1.9	115	2.6	8,340	1.6
<b>Total</b>	<b>447,749</b>	<b>100</b>	<b>62,486</b>	<b>100</b>	<b>15,581</b>	<b>100</b>	<b>4,434</b>	<b>100</b>	<b>530,250</b>	<b>100</b>

 Data include persons with diagnosed HIV infection regardless of stage of disease at diagnosis.

<sup>a</sup>Hispanics/Latinos can be of any race.

<sup>b</sup>Data have been statistically adjusted to account for missing transmission category.

<sup>c</sup>Heterosexual contact with a person known to have, or to be at high risk for, HIV infection.

<sup>d</sup>Includes persons whose infection was attributed to hemophilia, blood transfusion, or perinatal exposure or whose risk factor was not reported or not identified.

Note. Retention in care was defined as 2 or more CD4 or VL tests performed at least 3 months apart during 2012. Viral suppression was defined as a viral load result of <200 copies/mL.

\*Statistically significant compared with Metropolitan.