Published in final edited form as:

J Assoc Nurses AIDS Care. 2021 ; 32(5): 561–568. doi:10.1097/JNC.0000000000000249.

Barriers to HIV Care by Viral Suppression Status Among US Adults With HIV: Findings From the Centers for Disease Control and Prevention Medical Monitoring Project

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Abstract

Failure to maintain viral suppression may be attributed to suboptimal care engagement. Using data collected during 2015–2018, we describe nationally representative estimates of engagement in care among US adults with diagnosed HIV, overall and by viral suppression. Of those who felt they did not receive enough care, we described detailed information on barriers to care by viral suppression. We reported weighted percentages and evaluated differences between groups using Rao-Scott chi-square tests ($p < .05$). Persons who were not virally suppressed were less likely to be retained in care (57.3 vs. 90.8%). Common barriers to care included life circumstances that impeded receipt of care (50.0%), financial barriers (34.5%), and not feeling sick enough to take medicine (32.0%). Barriers to care varied by viral suppression status, and people who were not virally suppressed were more likely to report more than one barrier to care. These findings demonstrate that barriers can be multifaceted; addressing barriers to care by expanding comprehensive care models in HIV care settings could improve clinical outcomes among people with HIV.

Keywords

barriers to care; HIV care engagement; viral suppression

Background

During 2018, 58% of people with diagnosed HIV in the United States were retained in care (Centers for Disease Control and Prevention [CDC], 2020d). HIV care engagement is an important predictor of viral suppression—a key outcome for ending the US HIV epidemic (Cohen et al., 2014; Department of Health and Human Services, 2020). Disparities

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Author Contributions

S. Dasgupta conceived of and designed the analysis and wrote the paper; Y. Tie conducted the analysis and critically reviewed the paper; L. Beer provided input on the design of the analysis and critically reviewed the paper; J. Fagan contributed to the design of the analysis and critically reviewed the paper; J. Weiser contributed to the design of the analysis and critically reviewed the paper.

Disclosures

The authors report no real or perceived vested interests related to this article that could be construed as a conflict of interest.

in viral suppression may be attributed to differing levels of care access and engagement among selected populations. Barriers to HIV care may be categorized into domains, some of which include structural factors, such as provider availability and transportation; financial barriers, including health care coverage and poverty; personal circumstances, including co-occurring conditions (e.g., depression, substance use), incarceration, competing priorities, or personal health beliefs; and stigma and discrimination (Bradford et al., 2007). Identifying and addressing barriers to care, particularly among those who are not virally suppressed, may help improve HIV care engagement.

Although there is some existing literature on barriers to HIV care, many of these analyses are limited in scope, focused on certain geographic localities or populations, or not current (Dombrowski et al., 2015; Moneyham et al., 2010; Tobias et al., 2007; Yehia et al., 2015). We used nationally representative data from the Medical Monitoring Project (MMP) to assess HIV care engagement among adults with diagnosed HIV, overall and by viral suppression status. Among those who felt they did not receive enough HIV care, we describe detailed information on barriers to HIV care by viral suppression status.

Methods

The CDC MMP uses a two-stage sampling methodology. During the first stage, 16 states are sampled from all states, the District of Columbia, and Puerto Rico. In the second stage, simple random samples of adults with diagnosed HIV from sampled states are selected annually from the National HIV Surveillance System, a census of all persons with diagnosed HIV in the United States (Beer et al., 2019). For the 2015–2017MMP data cycles, data were collected during June of each cycle year through May of the following year via interview and medical record abstraction for 11,914 adults with diagnosed HIV. Because MMP is conducted as a part of routine public health surveillance, it is deemed to be nonresearch. Areas that participated in MMP obtained institutional review board approval as necessary; all participants provided informed consent (Beer et al., 2019). Participants were asked about engagement in HIV care, missed appointments, and whether they felt they received enough medical care. Persons who felt they did not receive enough care ($n = 965$) were asked about specific reasons for not being more engaged in HIV care, henceforth known as barriers to care. All measures were collected based on the past 12 months.

Retention in care was defined as receiving two or more indicators of outpatient HIV care three or more months apart in the past 12 months. Receipt of outpatient HIV care was obtained through abstraction of medical records and “defined as any documentation of the following: encounter with an HIV care provider (could also be self-reported), viral load test result, CD4 test result, HIV resistance test or tropism assay, antiretroviral therapy (ART) prescription, *Pneumocystis pneumonia* prophylaxis, or MAC prophylaxis” (CDC, 2020a, p. 14). Sustained viral suppression was defined as having all viral load measurements documented in medical records as undetectable or less than 200 copies/mL in the past 12 months (CDC, 2020a).

Among all adults with diagnosed HIV, we reported measures of HIV care engagement, overall and by viral suppression status. Among persons who felt they did not receive enough care, we assessed barriers to care, overall and by viral suppression. We reported weighted percentages and corresponding 95% confidence intervals (CIs) and used Rao-Scott chi-square tests to assess differences between groups ($p < .05$). All analyses were weighted based on known probabilities of selection, adjusted for nonresponse, and poststratified to National HIV Surveillance System population totals by age, race/ethnicity, and sex at birth (CDC, 2020a). All analyses were conducted using SAS (SAS version 9.4; SAS Institute, Inc., Cary, NC).

Results

During 2015–2018, nearly 80% of adults with diagnosed HIV were retained in HIV care, 24.0% had missed at least 1 visit with a health care provider, and 36.3% had at least one unsuppressed viral load test in the past year (Table 1). Nearly two thirds (63.7%) of adults with diagnosed HIV had sustained viral suppression. Persons who were not virally suppressed were less likely to be retained in care (57.3 vs. 90.8%; $\chi^2 = 653$; $P < .0001$), and more likely to miss health care visits (31.1 vs. 20.0%; $\chi^2 = 83$; $p < .0001$) and get professional help to receive more care (19.0 vs. 11.2%; $\chi^2 = 88$; $P < .0001$).

Among adults with diagnosed HIV who felt they did not receive enough HIV care, only 38.8% had sustained viral suppression (Table 2). Nearly all reported at least one barrier to care (95.6%), and nearly two thirds (62.6%) of them reported more than one barrier (Table 2). Common barriers to care included having life circumstances that impeded receipt of care (50.0%) or problems with money or insurance (34.5%), not feeling sick enough to take medicine (32.0%), and health care providers not requesting more frequent appointments (31.5%). In addition, 17.1% reported fear of HIV disclosure, 14.7% said they did not like or trust their HIV care providers, 14.2% reported fear or denial about living with HIV, and 8.3% did not believe that ART would improve their health.

Compared with those who were virally suppressed, persons who were not virally suppressed were more likely to report life circumstances that impeded care engagement (56.6 vs. 39.7%; $\chi^2 = 6.8$; $p < .0001$), problems with money or insurance (39.1 vs. 27.4%; $\chi^2 = 10$; $p = .002$), and fear or denial about living with HIV (18.6 vs. 7.4%; $\chi^2 = 15.7$; $p < .0001$) as barriers to care. Persons who were not virally suppressed were less likely to report their health care provider not requesting more frequent appointments (22.3 vs. 46.1%; $\chi^2 = 40.6$; $p < .0001$) as a barrier to care. Persons who were not virally suppressed were also more likely to report more than one barrier to care (65.7 vs. 57.6%; $\chi^2 = 6.1$; $p = .014$).

Discussion

This was the first analysis to report nationally representative estimates of HIV care engagement and detailed information on barriers to care by viral suppression status among adults with diagnosed HIV in the United States. We found that people with diagnosed HIV who were not virally suppressed were less likely to be engaged in HIV care and were more likely to miss visits and feel they did not receive enough HIV care. Among people who felt they did not receive enough HIV care, almost all reported at least one barrier and nearly two thirds of them reported multiple barriers. People who were not virally suppressed were more likely to report more than one barrier to care. People who were not virally suppressed were also more likely to report life circumstances that impeded HIV care engagement, financial issues, and fear or denial about living with HIV as barriers to care.

Half of adults with diagnosed HIV, including a majority of those who were not virally suppressed, reported having life circumstances that impeded HIV care engagement. Issues related to substance use, mental health, homelessness, and poverty are common life circumstances experienced by people with HIV (CDC, 2020a) that may affect care engagement. Leveraging resources that support a comprehensive care model, such as the Ryan White HIV/AIDS Prevention (RWHAP) funding, could increase access to ancillary care services to address barriers to care. RWHAP-funded facilities are more likely to have colocated ancillary care services not just for HIV but also for co-occurring morbidities, such as substance use and mental health disorders, and social services, such as housing and food assistance (Beane et al., 2014; Weiser et al., 2015). These wraparound services are essential for people with HIV who have social determinants associated with poor health and comorbid conditions. Ancillary care services, such as transportation assistance, meal or food services, and shelter or housing assistance, may help address financial barriers to care engagement, which were especially prominent among those who were not virally suppressed.

There are currently many high-impact interventions focused specifically on addressing barriers to HIV care. For example, Anti-Retroviral Treatment and Access to Services is a model that aims to establish a strong relationship between people with recent HIV diagnoses and linkage to a care coordinator to provide adequate resources to successfully engage in care (CDC, 2020b; Craw et al., 2010). Stay Connected is an intervention that focuses on building relationships between people living with HIV and providers, including patient navigators, to address challenges to engaging in medical care. Providing referrals for key support services, including for mental health and substance use, is an important tenet of this program. Using such interventions alongside a data-to-care approach may be an effective strategy in identifying and addressing barriers to HIV care and re-engaging people in care (CDC, 2020b). Although persons who were not virally suppressed experienced substantial barriers to receiving HIV care, they were also more likely to get professional help to increase their access to care, which suggests that the RWHAP and these high-impact interventions may be appropriately targeting persons who are not virally suppressed. However, only one in five persons who were not virally suppressed reported receiving such services, indicating substantial room for improvement.

We found that fear or denial about living with HIV was more likely to be reported as a barrier to HIV care among those who were not virally suppressed. These feelings may be related to HIV stigma, which has long been known to be a substantial barrier to care among people living with HIV and could be experienced in health care settings (Rice et al., 2017; Turan, Hatcher, et al., 2017; Turan, Rogers, et al., 2017). Combatting stigma has been prioritized as a part of the national Ending the HIV Epidemic initiative (Department of Health and Human Services, 2020). The CDC’s longstanding Let’s Stop HIV Together campaign focuses on highlighting the role of the community to work together in reducing stigma through programs like Stop HIV Stigma (CDC, 2020c). Decreasing health care–related stigma and discrimination through provider trainings and implementation of policies, emphasizing the importance of inclusivity, may also help improve HIV care engagement, particularly among persons who are not virally suppressed.

We found that health-related beliefs, including not believing taking ART would improve health and distrust of HIV providers, may also have affected HIV care engagement. Previous studies have shown that commonly cited reasons for resisting ART medications included preferences for alternative medicine or care; concerns about long-term effects of medication, including toxicity; and mistrust of medication and HIV care providers (Beer et al., 2009, 2012; Randolph et al., 2020; Relf et al., 2019). Engaging in a dialogue about the importance of HIV care engagement and regularly taking ART during HIV care visits, including elicitation of patient perspectives, may help address negative beliefs about ART and mistrust of providers.

These findings are subject to several limitations. First, because information obtained from participant interviews were based on self-report, there was potential for information bias. Next, not every person sampled participated in MMP. However, standard methodology was used to adjust findings for nonresponse. Even with suboptimal response rates, findings obtained using unbiased sampling methodology have considerable value (Wittwer & Hubrich, 2015). Third, specific information about life circumstances that impeded receipt of care, such as substance use, mental health issues, or incarceration, was not ascertained for all participants. Questions related to barriers to care could have been interpreted differently, potentially yielding different responses for certain people. Finally, data on barriers to care were only collected among persons who felt they did not receive adequate care.

These findings underscore the importance of addressing barriers to care, particularly among people who are not virally suppressed. We demonstrated that barriers can be multifaceted and that a large proportion experienced multiple barriers to care. Continued efforts to address barriers to care through high-impact programs and leveraging a comprehensive care model in HIV care settings may improve HIV clinical outcomes, particularly in vulnerable populations.

Acknowledgments

The authors acknowledge local MMP staff, health departments, and MMP participants, without whom this work would not be possible. The United States CDC funded data collection and other activities related to the MMP.

Disclaimer

The findings and conclusions in this report are those of the authors and do not necessarily represent the views of the CDC.

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Key Considerations

- Among persons with diagnosed HIV who felt they did not receive enough HIV care, common barriers to care included life circumstances that impeded receipt of care, financial barriers, and not feeling sick enough to take medicines; almost all reported at least one barrier and nearly two thirds of them reported multiple barriers.
- People who were not virally suppressed were more likely to report more than one barrier to care and were also more likely to report life circumstances that impeded HIV care engagement, financial issues, and fear or denial about being HIV positive as barriers to care.
- Barriers to HIV care can be multifaceted, and a large proportion of persons with HIV experience multiple barriers to care; continued efforts to address barriers to care through high-impact programs and leveraging a comprehensive care model in HIV care settings may improve HIV clinical outcomes, particularly in vulnerable populations.

Table 1.

Prevalence of Sustained Viral Suppression Among Adults With Diagnosed HIV, Overall and by Selected Characteristics—United States, 2015–2018 (*N* = 11,914)[a]

	Overall		Had Sustained Viral Suppression[b]		Did Not Have Sustained Viral Suppression				
	N	**Weighted Column % (95% CI)**	***n***	**Weighted Column % (95% CI)**	***n***	**Weighted Column % (95% CI)**	χ^2	**df**	***p*-Value**
Total (row %)	11,914		8,089	63.7 (62.0–65.4)	3,825	36.3 (34.6–38.0)			
Retained in HIV care[c]							653	1	<.0001
Yes	9,915	79.3 (77.9–80.8)	7,467	90.8 (89.5–92.1)	2,448	57.3 (54.9–59.7)			
No	1,691	20.7 (19.2–22.1)	622	9.2 (7.9–10.5)	1,069	42.7 (40.3–45.1)			
No. of visits with any outpatient HIV care provider							296	4	<.0001
0	271	4.3 (3.6–4.9)	82	1.0 (0.7–1.3)	189	10.2 (8.4–12.0)			
1	688	6.7 (5.9–7.6)	403	5.6 (4.6–6.6)	285	8.8 (7.5–10.0)			
2	2,484	21.7 (19.8–23.6)	1,851	23.8 (21.6–26.0)	633	17.8 (15.5–20.2)			
3	1,997	16.7 (15.7–17.7)	1,482	18.6 (17.4–19.7)	515	13.3 (11.8–14.8)			
≥4	6,257	50.6 (48.3–52.9)	4,182	51.0 (48.3–53.7)	2,075	49.9 (47.4–52.5)			
Any missed visits with a health care provider							83	1	<.0001
Yes	2,819	24.0 (22.8–25.1)	1,604	20.0 (18.8–21.2)	1,215	31.1 (28.8–33.3)			
No	8,974	76.0 (74.9–77.2)	6,439	80.0 (78.8–81.2)	2,535	68.9 (66.7–71.2)			
Perceived frequency of HIV care visits							213	1	<.0001
More than needed or about the right number needed	10,779	89.9 (89.0–90.7)	7,570	93.9 (93.3–94.5)	3,209	82.5 (80.5–84.5)			
Less than what was needed	965	10.1 (9.3–11.0)	460	6.1 (5.5–6.7)	505	17.5 (15.5–19.5)			
Received help from a professional to receive more outpatient HIV medical care							88	1	<.0001
Yes	1,596	14.0 (13.1–14.9)	887	11.2 (10.3–12.1)	709	19.0 (17.4–20.7)			
No	10,203	86.0 (85.1–86.9)	7,159	88.8 (87.9–89.7)	3,044	81.0 (79.3–82.6)			
Attended a RWHAP-funded facility for usual source of HIV care							4	1	0.050
Yes	7,904	69.5 (64.1–74.8)	5,425	68.3 (62.6–74.1)	2,479	71.9 (66.6–77.2)			
No	3,395	30.5 (25.2–35.9)	2,513	31.7 (25.9–37.4)	882	28.1 (22.8–33.4)			

Note. CI 5 confidence interval; RWHAP 5 Ryan White HIV/AIDS Program.

[a] All data are presented based on the past 12 months.

[b] Sustained viral suppression was defined as having all viral load measurements in the past 12 months documented undetectable or <200 copies/mL.

[c] Retention in care was defined as having ≥2 elements of outpatient HIV care ≥3 months apart in the past 12 months.

Table 2.

Barriers to HIV Care Among Adults With Diagnosed HIV Who Felt They Did Not Receive Enough HIV Care in the Past 12 Months, Overall and by Selected Characteristics—United States, 2015–2018 ($n = 965$)

	Overall		**Had Sustained Viral Suppression**[a]		**Did Not Have Sustained Viral Suppression**				
	n	**Weighted Column %(95% CI)**	***n***	**Weighted Column %(95% CI)**	***n***	**Weighted Column %(95% CI)**	**χ^2**	**df**	***p*-Value**
Total (row%)	965		460	38.8 (34.5–43.1)	505	61.2 (56.9–65.5)			
Reported any barrier to care							—	—	—
Yes	918	95.6 (93.9–97.2)	429	93.1 (90.2–96.0)	489	97.1 (95.2–99.0)			
No	45	4.4 (2.8–6.1)	29	6.9 (4.0–9.8)	16	*b*			
Reported >1 barrier to care							6.1	1	.014
Yes	593	62.6 (58.7–66.4)	262	57.6 (52.6–62.7)	331	65.7 (60.8–70.6)			
No	370	37.4 (33.6–41.3)	196	42.4 (37.3–47.4)	174	34.3 (29.4–39.2)			
Having life circumstances that impeded receipt of care							16.8	1	<.0001
Yes	475	50.0 (45.9–54.1)	189	39.7 (33.9–45.5)	286	56.6 (51.1–62.0)			
No	488	50.0 (45.9–54.1)	270	60.3 (54.5–66.1)	218	43.4 (38.0–48.9)			
Problems with money or health insurance							10	1	.002
Yes	304	34.5 (30.8–38.3)	122	27.4 (22.7–32.0)	182	39.1 (33.6–44.5)			
No	657	65.5 (61.7–69.2)	336	72.6 (68.0–77.3)	321	60.9 (55.5–66.4)			
Did not feel sick							0.3	1	.565
Yes	292	32.0 (28.0–36.1)	141	30.7 (25.4–36.0)	151	32.8 (27.5–38.2)			
No	670	68.0 (63.9–72.0)	317	69.3 (64.0–74.6)	353	67.2 (61.8–72.5)			
Health care provider did not request more frequent appointments					40.6	1	<.0001		
Yes	334	31.5 (27.6–35.5)	207	46.1 (40.6–51.6)	127	22.3 (17.4–27.1)			
No	625	68.5 (64.5–72.4)	250	53.9 (48.4–59.4)	375	77.7 (72.9–82.6)			
Had trouble finding transportation							0.8	1	.374
Yes	252	27.1 (23.0–31.3)	107	25.3 (20.7–29.8)	145	28.3 (22.6–34.1)			
No	711	72.9 (68.7–77.0)	352	74.7 (70.2–79.3)	359	71.7 (65.9–77.4)			
Could not find an HIV provider at all or one that met needs						1.1	1	0.303	

	Overall		Had Sustained Viral Suppression[a]		Did Not Have Sustained Viral Suppression				
	n	Weighted Column %(95% CI)	*n*	Weighted Column %(95% CI)	*n*	Weighted Column %(95% CI)	χ^2	df	*p*-Value
Yes	170	18.3 (15.4–21.2)	75	16.3 (12.4–20.2)	95	19.5 (15.2–23.8)			
No	792	81.7 (78.8–84.6)	382	83.7 (79.8–87.6)	410	80.5 (76.2–84.8)			
Did not want anyone to know about HIV status							3.5	1	.063
Yes	142	17.1 (13.8–20.5)	56	13.8 (10.0–17.6)	86	19.2 (14.6–23.9)			
No	820	82.9 (79.5–86.2)	403	86.2 (82.4–90.0)	417	80.8 (76.1–85.4)			
Do not like or trust health care providers							1.7	1	.189
Yes	139	14.7 (11.8–17.6)	53	12.1 (7.7–16.4)	86	16.4 (12.3–20.5)			
No	821	85.3 (82.4–88.2)	406	87.9 (83.6–92.3)	415	83.6 (79.5–87.7)			
Fear or denial about living with HIV							15.7	1	<.0001
Yes	114	14.2 (11.0–17.4)	30	7.4 (4.4–10.4)	84	18.6 (13.8–23.4)			
No	849	85.8 (82.6–89.0)	429	92.6 (89.6–95.6)	420	81.4 (76.6–86.2)			
Did not believe ART would improve health							6.4	1	.012
Yes	73	8.3 (6.1–10.5)	24	5.2 (3.0–7.5)	49	10.2 (7.0–13.5)			
No	882	91.7 (89.5–93.9)	433	94.8 (92.5–97.0)	449	89.8 (86.5–93.0)			
Other reason							0.1	1	.755
Yes	54	4.5 (3.0–6.0)	24	4.2 (2.3–6.2)	30	4.7 (2.6–6.7)			
No	908	95.5 (94.0–97.0)	434	95.8 (93.8–97.7)	474	95.3 (93.3–97.4)			

Note. ART = antiretroviral therapy; CI = confidence interval.

[a] Sustained viral suppression was defined as having all viral load measurements in the past 12 months documented undetectable or < 200 copies/mL.

[b] Estimates with a coefficient of variation ≥ 0.30, and associated statistical testing results, are suppressed due to unreliability.