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Systematic monitoring of retention in care in U.S.-based HIV care facilities

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Abstract

National guidelines recommend that HIV providers systematically monitor retention in care to identify and re-engage persons suboptimally in care. We described (1) U.S.-based outpatient HIV care facilities that systematically monitor retention in care, and (2) characteristics of patients attending facilities that monitored retention in care. We used data collected during 6/2014–5/2015 from the Medical Monitoring Project, an annual, cross-sectional survey that produces nationally representative estimates of characteristics of HIV-positive persons in medical care. We described systematic monitoring of retention in care among facilities and patients attending facilities providing this service using weighted percentages and 95% confidence intervals, and used Rao-Scott chi-square tests ($p < .05$) to assess differences by selected characteristics. Overall, 67% of facilities systematically monitored retention in care, and 81% of patients attended these facilities. Federally qualified health centers, community-based organizations, health departments, non-private practices, and Ryan White HIV/AIDS Program (RWHAP)-funded facilities were more likely to systematically monitor retention in care. Persons living in poverty, and those who were homeless or incarcerated, or injected drugs were more likely to attend facilities with this service. Although systematic monitoring of retention in care is accessible for many patients, improvements at other, non-RWHAP-funded facilities may help in reaching national prevention goals.

Keywords

HIV; care; systematic monitoring; retention

Background

Antiretroviral therapy (ART) has revolutionized HIV treatment and care, and when taken appropriately, results in viral suppression, which reduces morbidity and mortality and minimizes risk of transmitting HIV to others (Bavinton et al., 2017; Cohen et al., 2016; Palella et al., 1998; Rodger et al., 2016; The Lancet, 2017). However, engagement in HIV medical care is critical for ART prescription and adherence to occur, and thus, increasing the percentage of persons with HIV who are linked and retained in HIV care is a national priority (Bradley et al., 2014; HRSA, 2015). To ensure patients are engaged

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in HIV medical care, the International Association of Providers of AIDS Care strongly recommends that HIV care providers systematically monitor retention in care of their patients to identify persons out of care and re-engage them as needed (Thompson et al., 2012). Systematic monitoring of retention can be done through review of facility medical records and surveillance data, and can be used to identify gaps in HIV care, visit adherence, and time between visits. HIV outpatient care facilities can then use these data to follow up with patients needing additional care (Thompson et al., 2012).

Recently published findings reported that 53% of HIV care providers practiced in facilities that offered systematic monitoring of retention in care (Craw et al., 2017). However, the extent to which these guidelines are generally integrated into the outpatient HIV care facility setting is unknown. There is also limited information about the proportion of patients attending facilities that systematically monitor retention in care and characteristics of these patients. Thus, in this analysis, we described (1) the proportion of U.S.-based outpatient HIV care facilities in the United States that systematically monitor retention in care of patients, overall and by facility characteristics, and (2) characteristics of HIV patients who attended facilities that monitored retention in care.

Methods

Data and measures

The Medical Monitoring Project (MMP) is an annual cross-sectional survey designed to provide nationally representative estimates of behavioral and clinical characteristics of HIV-positive persons in medical care. MMP utilized a three-stage probability-proportional-to-size sampling design during 2014, in which states and territories were sampled first, then HIV outpatient care facilities within those areas were sampled with probability-proportional-to-size based on the number of persons receiving care for HIV, and finally, persons with diagnosed HIV aged 18 years and older who had at least 1 medical care visit in a sampled facility during January–April 2014 were sampled. MMP is conducted as a part of routine surveillance and thus is deemed to be non-research; participating states or territories as well as facilities obtained institutional review board approval for data collection as needed, and informed consent was obtained from all interviewed participants.

All data were collected during June 2014–May 2015. All sampled states and territories participated in MMP, and included California (including the separately funded areas, Los Angeles County and San Francisco), Delaware, Florida, Georgia, Illinois (including Chicago), Indiana, Michigan, Mississippi, New Jersey, New York (including New York City), North Carolina, Oregon, Pennsylvania (including Philadelphia), Puerto Rico, Texas (including Houston), Virginia, and Washington. The overall facility response rate was 86% and patient response rate was 56%. Data were weighted based on known probabilities of selection at state or territory, facility, and patient levels, and for patient and facility nonresponse.

Local MMP staff collected information about all eligible, sampled outpatient HIV care facilities from facility staff and through other sources, such as facility web-pages. Data were obtained on whether facilities had programs in place for systematic monitoring of retention

in care. Information about facility type, including whether or not the facility was a private practice, hospital-based setting, federally qualified health center (FQHC), community-based organization (CBO), or health department (HD) was collected. Facility ownership (public or private) and receipt of Ryan White HIV/AIDS Program (RWHAP) funding were also ascertained.

In addition to facility-level characteristics, self-reported demographic and behavioral characteristics were collected from patients receiving care at these facilities through telephone or face-to-face interviews. Clinical data were recorded by medical record abstraction. Patients were interviewed about demographic characteristics, such as age, gender, sexual orientation, race/ethnicity, educational attainment, health insurance coverage, household income with respect to the federal poverty line according to the Department of Health and Human Services poverty guidelines (2013 Poverty Guidelines), history of homelessness and incarceration in the past 12 months, as well as behavioral characteristics such as injection and non-injection drug use in the past 12 months and binge drinking, defined as four (among females) or five (among males) or more alcoholic drinks in one sitting during the previous 30 days. Race and ethnicity were categorized as: non-Hispanic white, non-Hispanic black/African American (henceforth known as black), Hispanic/Latino, and other. Health insurance coverage was summarized into a single variable categorized as any private insurance, only public insurance, and only Ryan White coverage/uninsured. All self-reported information was based on the 12 months prior to interview, except where otherwise specified.

Analysis

We examined the proportion of outpatient HIV care facilities ($n = 560$) with programs for systematic monitoring of retention in care. Of facilities that had information on systematic monitoring programs ($n = 462$), we examined the proportion that systematically monitored retention in care overall and by facility type, ownership, and receipt of RWHAP funding. We assessed differences in systematic monitoring by facility characteristics. We then examined the proportion of HIV patients ($n = 4,605$) who attended an HIV care facility with systematic monitoring of retention, overall and by demographic and behavioral characteristics, and assessed differences in attendance at a facility with systematic monitoring by patient characteristics. We reported facility and patient characteristics with weighted percentages and corresponding 95% confidence intervals (CIs). We used Rao-Scott chi-square tests to assess statistical differences between groups, where $p < .05$ signified statistical significance. All analyses accounted for complex sample design and unequal selection probabilities and were conducted using SAS survey procedures.

Results

Of all outpatient HIV care facilities, 67% had programs to systematically monitor retention in care of all patients in place (Table 1). Facilities more likely to have programs for systematic monitoring of retention in care included non-private practices, compared with private practices (82% vs. 55%; $p < .0001$); FQHCs, compared with non-FQHCs (96% vs. 59%; $p < .0001$); CBOs versus non-CBOs (95% vs. 62%; $p < .0001$); and clinics located in

health departments versus those not located in health departments (91% vs. 66%; $p = .0089$). Facilities that received RWHAP funding were more likely to have systematic monitoring of retention in care in place, compared with facilities that did not receive RWHAP funding (92% vs. 51%; $p < .0001$).

Overall, 81% of persons attended an outpatient HIV care facility with a program for systematic monitoring of retention in care (Table 2). Persons more likely to attend such facilities included females, compared with males (83% vs. 80%; $p = .0408$), those with lower educational attainment (less than high school education, 86%; high school or equivalent, 82%; more than high school, 79%; $p = .0024$), persons at or below the poverty level, compared with persons above the poverty level (84% vs. 78%; $p = .0053$), and those who reported being homeless during the previous 12 months, compared with persons not being homeless (89% vs. 80%; $p = .0009$). Attendance at a facility with systematic monitoring varied by sexual orientation (homosexuals, 78%; heterosexuals, 83%; bisexuals, 84%; $p = .0072$), racial/ethnic categories (non-Hispanic whites, 76%; non-Hispanic blacks, 84%; Hispanic/Latinos, 83%; other racial/ethnic group, 81%; $p = .0014$), and health insurance coverage (private insurance, 74%; public insurance only, 83%; Ryan White coverage only or uninsured, 88%; $p < .0001$). In addition, persons who reported being incarcerated during the previous 12 months, compared with those who did not (91% vs. 81%; $p < .0001$), and those who reported injecting drugs during the last year, compared with those who did not (90% vs. 81%; $p = .0218$), were more likely to receive care at an HIV care facility with systematic monitoring programs.

Discussion

This was the first analysis to examine availability of systematic monitoring of retention in care using a nationally representative sample of U.S.-based outpatient HIV care facilities. The findings demonstrated that one-third of facilities did not systematically monitor retention in care for all HIV patients, despite strong recommendations to do so (Thompson et al., 2012). Overall, 81% of patients attended facilities with systematic monitoring of retention in care. Facilities that served persons living in poverty and at high risk for poor HIV outcomes, particularly RWHAP-funded facilities, were more likely to systematically monitor retention in care.

Using facility and surveillance data to monitor appointment attendance and gaps in care is central to CDC's Data to Care activities (CDC). Through the Data to Care program, CDC encourages local jurisdictions to support the HIV care continuum and national HIV prevention goals by identifying and re-engaging persons with diagnosed HIV who are in need of HIV care services, or may need support to improve ART adherence and viral suppression. HIV surveillance data can be used to identify such persons. Facility data on patients also offer unique information that surveillance data do not, such as documentation of missed HIV care visits, which has been highly associated with all-cause mortality (CDC; Mugavero et al., 2009; Thompson et al., 2012). Incorporating both of these data sources may provide a more complete picture of HIV care engagement among patients. Combining all available information at the level of the jurisdiction may be especially important for patients attending more than one facility for HIV care needs, as these patients may be

documented as being out of care in any given facility, but actually are retained in care when looking at all attended facilities. However, using all available databases to systematically monitor retention in care may require coordination within facilities, and between local health departments and health facilities. Publicly-funded facilities, such as RWHAP-funded facilities, health departments, and FQHCs, may have stronger coordination within and between organizations, which may make them more likely to have successful programs for systematic monitoring of retention in care.

There may be several challenges with systematic monitoring of retention. For instance, some facility systems may have limitations in recording and accessing clinic-based information through electronic health records because of lack of information technology (IT) capacity and having multiple data systems to track information without means for integration. With continued public health funding cuts, there also may be limitations in facility staffing needed to lead efforts to monitor retention in care in publicly-funded facilities. There may also be limited personnel for reaching out to patients identified as being suboptimally in care, which, although potentially quite resource-intensive, is crucial to the success of systematic monitoring of retention efforts. Non-RWHAP-funded facilities without co-located services may have more challenges with systematic monitoring of retention in care because of any of these reasons. Facilities which experience these challenges could consider leveraging external connections with health departments, data to care systems, and local disease intervention specialists to help support systematic monitoring programs. Successful coordination between multiple service providers and the health department also requires adequate personnel and support at both levels, and integration in potentially multiple database systems. Utilizing already existing resources and connections with external organizations may be extremely helpful in finding difficult to reach persons who are out of care (Dombrowski et al., 2018). Identifying and addressing reasons for not implementing a systematic monitoring program may be helpful in expanding the use of data to improve retention in care.

These findings demonstrated that compared with other outpatient HIV care facilities, RWHAP-funded facilities, which serve underinsured or uninsured HIV-positive persons who might otherwise not be able to receive care (HRSA), are more likely to systematically monitor retention in care. Systematic monitoring of retention in care is a vital part of identifying and re-engaging HIV-positive persons who are out of care or suboptimally in care and can be used to provide support to retain patients, which may be critical for achieving viral suppression among patients attending these facilities (Doshi et al., 2015; Thompson et al., 2012). Monitoring retention may be particularly important for persons who have previously been found to be less engaged in HIV care, such as persons identifying as non-white, and those reporting being homeless, being in jail/prison, and injecting drugs during the previous 12 months (Aidala, Lee, Abramson, Messeri, & Siegler, 2007; “Announcement: Monitoring Selected National HIV Prevention and Care Objectives,” 2017; Dasgupta, Oster, Li, & Hall, 2016; Iroh, Mayo, & Nijhawan, 2015). RWHAP-funded facilities also provide a wide range of medical and ancillary services that additionally support retention in care and ART adherence by addressing immediate needs, such as shelter or housing assistance; offering comprehensive health services, such as for mental health and substance use; and providing other support services, such as adherence counseling,

transportation assistance, and case management (Holtzman, Brady, & Yehia, 2015; HRSA; Thompson et al., 2012; Weiser et al., 2015). Ultimately, using evidence-based strategies, such as systematic monitoring and co-location of medical services, to improve HIV care engagement should be considered to ensure patients become and remain virally suppressed (Holtzman et al., 2015; Thompson et al., 2012).

There are some limitations to this analysis. First, information on systematic monitoring of retention in care was not available for 17% of outpatient HIV care facilities. Also, not all sampled facilities or HIV patients participated in MMP, although results were adjusted for nonresponse using standard methodology (Iachan et al., 2016). Even with suboptimal response rates, however, there is still value in results obtained from unbiased sampling methods (Groves, 2006). All patient characteristics were based on self-report and may be subject to misclassification, although we do not suspect any measurement error to be differential with respect to attendance at a facility with systematic monitoring of retention.

Conclusions

Systematic monitoring of retention in care for all persons with HIV is nationally recommended (Thompson et al., 2012), yet a third of U.S. outpatient HIV care facilities had no program for such monitoring. However, 81% of HIV patients attended a facility with a monitoring program. Nearly all RWHAP-funded facilities systematically monitored retention in care. Persons who reported being poor or who may be at high risk for unfavorable HIV outcomes were more likely to attend a facility with systematic monitoring of retention in care. Although many patients who might need additional support for HIV care engagement attend facilities that provide this assistance, reaching national goals to retain at least 90% of persons with diagnosed HIV in medical care may require improvements at other, non-RWHAP-funded facilities. Better coordination and integration of resources between facilities and health department data to care programs may help in establishing and maintaining systematic monitoring of retention in care programs.

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Table 1.

Characteristics of facilities with systematic monitoring of retention in care – Medical Monitoring Project, 2014.[a]

	Overall		Has systematic monitoring		
	n	**Weighted Column % (95% CI)**	***n***	**Weighted Row % (95% CI)**	***p***
Overall	462	-	334	67 (58–76)	
Facility type (not mutually exclusive categories)					
Private practice					<.0001
Yes	187	56 (47–65)	108	55 (42–68)	
No	264	44 (36–53)	218	82 (74–89)	
Hospital-based					0.575
Yes	152	30 (21–39)	108	71 (56–86)	
No	299	70 (61–79)	217	66 (57–75)	
Federally qualified health center					<.0001
Yes	101	24 (15–33)	95	96 (92–100)	
No	321	76 (67–85)	210	59 (47–71)	
Community-based organization					<.0001
Yes	72	16 (9–24)	65	95 (91–99)	
No	372	84 (76–91)	255	62 (52–72)	
Health department					0.0089
Yes	54	8 (5–11)	48	91 (82–100)	
No	388	92 (89–95)	271	66 (56–76)	
University-affiliated, teaching, academic facility					0.2084
Yes	113	17 (10–24)	87	73 (59–86)	
No	333	83 (76–90)	235	64 (55–74)	
Tertiary care facility					0.4536
Yes	54	8 (6–10)	40	72 (57–87)	
No	383	92 (90–94)	274	66 (56–75)	
Facility ownership					0.0633
Publicly owned	121	18 (11–25)	99	79 (69–89)	
Privately owned	312	82 (75–89)	214	64 (54–75)	
Ryan White HIV/AIDS Program funding					<.0001

	Overall		Has systematic monitoring		
	n	Weighted Column % (95% CI)	*n*	Weighted Row % (95% CI)	*p*
Yes	269	46 (35–57)	243	92 (87–97)	
No	163	54 (43–65)	75	51 (37–65)	

[a]Categories for some variables may not sum to total due to missing data.

Table 2.

Characteristics of patients attending facilities with systematic monitoring of retention in care – Medical Monitoring Project, 2014.[a]

	Overall		Attended a facility with systematic monitoring		
	n	**Weighted Column % (95% CI)**	***n***	**Weighted Row % (95% CI)**	***p***
Overall	4605	-	3703	81 (77, 85)	
Age, in years					0.0527
18–29	401	9 (8–11)	328	82 (76–88)	
30–39	661	15 (13–16)	555	84 (80–88)	
40–49	1279	28 (26–29)	1056	82 (78–87)	
≥50	2264	48 (47–50)	1804	79 (75–84)	
Gender					0.0408
Male	3304	75 (73–78)	2664	80 (76–84)	
Female	1226	25 (22–27)	1023	83 (79–88)	
Sexual orientation					0.0072
Homosexual	1868	43 (39–46)	1466	78 (74–83)	
Heterosexual	2257	48 (44–52)	1871	83 (78–87)	
Bisexual	430	10 (9–11)	363	84 (78–90)	
Race/ethnicity[b]					0.0014
Non-Hispanic white	1362	31 (25–37)	1027	76 (71–81)	
Non-Hispanic black	1915	41 (33–49)	1615	84 (80–89)	
Hispanic/Latino	1137	24 (17–30)	949	83 (78–88)	
Other	191	4 (4–5)	152	81 (72–89)	
Educational attainment					0.0024
Less than high school	938	20 (19–22)	807	86 (81–91)	
High school or equivalent	1336	29 (26–31)	1100	82 (78–86)	
More than high school	2331	51 (48–54)	1836	79 (74–83)	
Health insurance/coverage					<.0001
Any private insurance	1306	30 (27–32)	979	74 (69–80)	
Public insurance only	2588	56 (52–61)	2157	83 (79–87)	
Ryan White only/uninsured	619	14 (11–18)	538	88 (83–93)	
Poverty status					0.0053

	Overall		Attended a facility with systematic monitoring		
	n	Weighted Column % (95% CI)	*n*	Weighted Row % (95% CI)	*p*
Above poverty level	2036	47 (44–50)	1593	78 (73–83)	
At or below poverty level	2388	53 (50–57)	2005	84 (80–88)	
Homelessness, past 12 months					0.0009
Yes	384	9 (8–10)	338	89 (84–94)	
No	4221	91 (90–92)	3405	80 (76–84)	
Jail/prison, past 12 months					<.0001
Yes	196	5 (4–5)	176	91 (87–96)	
No	4408	96 (95–96)	3566	81 (76–85)	
Non-injection/injection drug use, past 12 months					0.1424
Yes	1192	27 (25–28)	983	83 (78–87)	
No	3388	73 (72–75)	2740	80 (76–85)	
Injection drug use, past 12 months					0.0218
Yes	116	2 (2–3)	103	90 (85–95)	
No	4463	98 (97–99)	3619	81 (77–85)	
Non-injection drug use, past 12 months					0.1449
Yes	1173	26 (24–28)	968	83 (78–87)	
No	3407	74 (72–76)	2755	80 (76–85)	
Binge drinking, past 30 days					0.1540
Yes	697	16 (14–17)	547	78 (72–84)	
No	3859	85 (83–86)	3154	81 (77–86)	

[a] Categories for some variables may not sum to total due to missing data.

[b] Racial/ethnic categories are mutually exclusive. Hispanics/Latinos can be of any race.

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