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Retention in Care Services Reported by HIV Care Providers in the United States, 2013 to 2014

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Abstract

Objectives—Evidence-based guidelines recommend that HIV care providers offer retention-in-care services, but data are needed to assess service provision.

Methods—We surveyed a probability sample of 1234 HIV care providers to estimate the percentage of providers whose practices offered 5 recommended retention services and describe providers' perceptions of barriers to care among patients.

Results—An estimated 21% of providers' practices offered all 5 retention services. Providers at smaller (<50 versus >400 patients), private, and non-Ryan White HIV/AIDS Program (RWHAP)-funded practices, and practices without on-site case management were significantly less likely to provide patient navigation services or do systematic monitoring of retention. Providers' most commonly perceived barriers to care among patients were mental health (40%), substance abuse (36%), and transportation (34%) issues.

Conclusion—Deficiencies in the provision of key retention services are substantial. New strategies may be needed to increase the delivery of recommended retention services, especially among private, non-RWHAP-funded, and smaller facilities.

Keywords

HIV; delivery of health care; retention in care; HIV care providers; Medical Monitoring Project

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The findings and conclusions in this report are those of the authors and do not necessarily represent the views of the Centers for Disease Control and Prevention (CDC).

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Declaration of Conflicting Interests

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Introduction

The US National HIV/AIDS Strategy (NHAS) updated to 2020 emphasizes the importance of monitoring and improving outcomes at all stages of the HIV care continuum, including the percentage of persons living with HIV who are diagnosed, engaged in care, on treatment, and virally suppressed.¹ According to national and local care continuum estimates, most persons living with HIV who are not virally suppressed have been diagnosed with HIV but are not engaged (linked and retained) in HIV care.^{2–5} Recently released guidelines and recommendations from HIV physician groups and federal agencies on HIV prevention and care in clinical settings endorse evidence-based strategies to retain patients in HIV care.^{6–10} Recommended retention strategies include providing colocated care and ancillary services, identifying and addressing individuals' barriers to care, providing patient or peer navigation services, and using HIV surveillance data and clinical data to identify and locate persons out of care.⁸ Several recent systematic literature reviews support using multiple strategies in combination to retain and reengage persons in HIV care.^{11–13}

The extent to which HIV care providers' practices are following recommendations to enhance patient engagement and retention in care is unknown. In 2013, the Medical Monitoring Project (MMP) constructed a national probability sample of HIV care providers working in a variety of clinical care settings across the United States and Puerto Rico. Using these data, we estimated the percentage of HIV care providers in the United States who offer recommended retention-in-care services in their practice and described providers' perceptions about reasons why patients miss scheduled follow-up visits.

Methods

We analyzed data collected from the MMP 2013–2014 Provider Survey, which was conducted in the geographic areas and HIV care facilities sampled for MMP in 2012.^{14,15} The Provider Survey used a complex 2-stage sample design, in which the US states and territories were sampled, followed by facilities providing HIV care in those jurisdictions. All 17 sampled jurisdictions (16 states and Puerto Rico) agreed to participate in MMP. Of 622 sampled facilities, 505 (81%) agreed to participate in the survey by providing contact information for all HIV care providers (defined as providers who order CD4 count or HIV viral load tests and/or prescribe antiretroviral medications). Providers (physicians, physician assistants, and nurse practitioners) were eligible to participate if they had completed professional training and had provided HIV care between January and April 2012. The final sample consisted of 2208 HIV care providers from 391 of 622 sampled facilities (63% overall facility cooperation rate), all of whom were invited to participate in the survey. Of 2208 providers sampled, 2023 (92%) were determined to be eligible and 1234 of the eligible providers returned surveys (American Association for Public Opinion Research, Response Rate 3,¹⁶ adjusted provider response rate, 64%). The data were weighted based on the probability of selection, and nonresponse adjustments were made to sampling weights based on provider and practice factors associated with nonresponse, for example, provider profession, number of HIV care providers in the practice, and whether or not the provider worked at a private practice.

Providers were recruited with a modified version of Dillman's Tailored Design Method,¹⁷ which involved mailing individualized recruitment packets to all of the providers in participating practices. The recruitment packets included a letter from the Centers for Disease Control and Prevention (CDC) explaining the purpose of the survey, instructions for completing the self-administered survey via paper or a Web-based response system, and a \$20 cash incentive. The recruitment materials explained the voluntary nature of the survey, and written informed consent was not obtained. As a public health surveillance activity, the MMP Provider Survey was determined to be nonresearch in accordance with federal human subjects' protections in the Code of Federal Regulations and CDC guidelines for defining public health research and nonresearch.^{18,19} Nonresponders were sent 3 additional mailings at set intervals over the following 7 weeks. Survey distribution and follow-up was conducted in waves comprising 8 individual cycles at 1 week intervals spanning 17 weeks between June 2013 and January 2014.

The provider survey instrument consisted of 61 questions covering 7 general content areas (provider demographics, professional characteristics, practice characteristics, general characteristics of their HIV patients, patient management practices, sources of information used for current guidelines and continuing education, and provision of antiretroviral prophylaxis for HIV-negative patients) and required approximately 30 minutes to complete. For this analysis, we focused on providers' reports about retention services (appointment reminders, patient navigation services, follow-up on missed visits, reinforcement of the importance of follow-up visits, and systematic monitoring of retention in care) offered to patients within their practices (Figure 1). We investigated bivariate associations between all 5 retention services being offered within one's practice and practice characteristics ascertained from facility data collected from clinic administrators for MMP. Practice characteristics evaluated included receipt of Ryan White HIV/AIDS Program (RWHAP) funding (yes or no), practice type (private or nonprivate), geographic location of practice (urban or nonurban), practice size (based on estimated HIV patient caseload), and provision of on-site case management services (yes or no). We also examined associations between the 2 retention services offered least often, systematic monitoring of retention in care and patient navigation services, with these practice characteristics.

We investigated providers' perceptions of their patients' barriers to care, measured as each provider's assessment of how frequently (never, rarely, sometimes, often, or very often) their patients miss scheduled visits due to the following reasons: child care problems, drug or alcohol abuse, emotional or psychological barriers related to HIV (eg, stigma, denial), homelessness, incarceration or legal detention, mental health problems, reluctance to admit not following provider's advice, too sick to travel to clinic, and transportation problems. Reasons for missed follow-up visits were considered endorsed if the provider responded that patients "often" or "very often" missed visits due to that particular reason.

We computed weighted estimates of percentages and corresponding 95% confidence intervals describing the population of HIV providers, whether their practice provided each of the 5 retention services, and their perceptions about why patients miss follow-up visits. Rao-Scott chi-square tests were performed to test bivariate associations between practice characteristics and offering all 5 retention services and offering the individual services of

patient navigation and systematic monitoring of retention in care. All estimates incorporated the survey weights, and variance estimates were computed using Taylor Series Linearization to reflect the complex features of the MMP provider sample. We used SAS/STAT (version 9.4; SAS Institute Inc) procedures for the analysis of complex sample survey data and considered estimates with a coefficient of variation >0.3 unreliable.

Results

Descriptive Statistics for Provider Population

Table 1 provides weighted estimates describing the population of HIV providers and characteristics of practices in which they work. Nearly 59% of providers were at least 50 years old, 57% were male, and 63% were white. Most HIV providers were physicians, board certified in infectious diseases (45%) or another specialty (30%), 15% were nurse practitioners, 5% physician's assistants, and 5% nonboard-certified physicians. Nearly 58% were HIV specialists, and 83% provided primary care. Among all HIV providers, 48% worked at RWHAP-funded practices and 42% worked in private practices (which may or may not have received Ryan White funds). Nearly 69% of providers worked at practices located in large metropolitan areas. With respect to the size of the practice, 29% worked in small practices (<50 patients), 45% worked in medium-sized practices (50–400 patients), and 25% worked in large practices (>400 patients). Nearly 51% of providers worked in practices offering on-site case management.

Retention-in-Care Services

The majority of providers worked in practices that reinforced the importance of follow-up visits (96%), used appointment reminders (89%), and followed up on missed visits (82%; Table 2). However, only 53% of providers worked in practices that conducted systematic monitoring of retention in care, and only 33% worked in practices that provided patient navigation services. An estimated 21% of providers worked in practices that provided all 5 retention services, 55% worked in practices that provided at least 4 retention services, and 84% worked in practices that provided at least 3 retention services (Figure 2).

Providers who worked in RWHAP-funded practices were considerably more likely than those in non-RWHAP-funded practices to report that their practice offered all 5 retention services (34% versus 9%), systematically monitored retention in care (77% versus 31%), and offered patient navigation services (45% versus 23%; Table 3). Providers who worked in nonprivate practices (versus private), large practices (versus medium or small), and practices that provided (versus did not provide) on-site case management were also more likely to report that their practice offered all 5 retention services, systematically monitored retention in care, and provided patient navigation services. Urban versus nonurban facility location was not associated with provision of retention services.

Providers' Perceived Reasons Why Patients Miss Scheduled Follow-up Visits

Mental health problems were reported by 41% of providers as often or very often being a reason for missed follow-up visits, followed by drug or alcohol abuse (36%), transportation

problems (34%), and emotional or psychological barriers associated with HIV (30%; Table 4).

Discussion

To our knowledge, these are the first national estimates on the provision of HIV retention-in-care services in clinical settings, and our findings suggest suboptimal delivery of recommended retention services in the United States. Only 1 in 5 HIV providers reported working in a practice that provided all 5 retention services, all of which are services recommended in recent HIV care guidelines.⁷⁻⁹ While a large majority reported working in practices that offered individual retention services such as appointment reminders and missed visit follow-up, just over half reported providing systematic monitoring of retention in care and only 1 in 3 reported providing patient navigation services. HIV providers at private, non-RWHAP-funded, and smaller facilities were even less likely to report that their facility provided all 5 retention services. Increasing provision of retention services within HIV care practices is needed to support the 2020 NHAS goal of increasing to 90% the percentage of persons with diagnosed HIV infection who are retained in HIV medical care.¹

Optimizing HIV care continuum outcomes requires that providers proactively identify and address barriers to care engagement in addition to offering recommended retention services.⁷ We found that providers endorsed reasons for missed patient visits (ie, mental health, substance abuse, transportation, and emotional or psychological barriers related to HIV) that are similar to those reported by patients as reasons for poor engagement in care.^{20,21} Reasons for missed visits such as mental health, substance abuse, or stigma are complex and multidimensional in nature and are not easily addressed directly by HIV care providers during follow-up care visits. Nonetheless, HIV providers have an integral role in screening for and identifying patients at risk of missed visits and linking patients to support services.

Previous data have shown that RWHAP-funded facilities were more likely than non-RWHAP-funded facilities to provide case management, mental health, and substance abuse treatment services, and patients attending RWHAP-funded facilities were more likely to report receiving these services than patients attending non-RWHAP-funded facilities.²² Colocating support services in settings providing routine HIV medical care is the cornerstone of the medical home model endorsed by RWHAP.²³ Expansion of the RWHAP medical home model might increase patient access to support services and foster enhanced engagement in care. In HIV practices where a medical home model cannot be implemented, administrators may consider colocating support staff (such as peer or patient navigators) who can refer or link patients to off-site support services. Similarly, HIV practices without colocated support services may consider strengthening linkages to RWHAP-funded service providers within existing referral networks to ensure that case management or patient navigation are provided to patients needing these services.

Guidelines from provider organizations and federal agencies emphasize the importance of implementing existing evidence-informed retention strategies in HIV practices as well as developing and disseminating new strategies to retain patients in HIV care.^{7,8} Organizations may consider leveraging existing resources, partnerships, and funded initiatives to increase

implementation of evidence-informed retention interventions in HIV care practices. Several federally funded programs are focused on identifying and promoting innovative methods and strategies to retain and reengage persons in HIV medical care. Centers for Disease Control and Prevention recently funded demonstration projects to implement and evaluate innovative approaches to improve linkage to and reengagement in HIV care among persons living with HIV.²⁴ Similarly, the Health Resources and Services Administration (HRSA) funds RWHAP Part C grantees through its Early Intervention Services and Capacity Development Grants programs to implement activities that establish or enhance infrastructure for improving the delivery of comprehensive HIV primary care services, including linkage or retention-in-care activities.²⁵ Last, current HRSA Special Projects of National Significance initiatives are focused on identifying and disseminating evidence-informed interventions to improve outcomes along the HIV care continuum.²⁶

Our analysis is subject to a few limitations. First, estimates of delivery of retention services are self-reported and may be subject to measurement error due to poor recall or social desirability. Provision of certain retention services may be performed by nonclinical staff, and thus providers may not have been aware of these services. However, provider awareness of services is important to measure, as it may reflect how often these services are promoted to patients. Next, estimates of retention services reflect the proportion of providers working in practices that offer each retention service, not the proportion of practices offering each service nor the overall proportion of HIV patients with access to these services. The proportion of patients with access to retention services may be higher than our provider-based estimates suggest, given that HIV care practices with larger patient volumes are more likely to provide these services. Nonetheless, our analyses provide valuable insight about HIV providers' perceptions and characteristics of HIV practices where service delivery can be enhanced.

Conclusion

HIV provider organizations and federal agencies emphasize the importance of offering comprehensive retention services in HIV clinical care. However, implementation of systematic monitoring of retention in care and patient navigation services in providers' practices is suboptimal, particularly among providers at private, non-RWHAP-funded, and smaller HIV care facilities. HIV care providers indicated that mental health concerns, substance abuse, lack of transportation, and psychological barriers related to HIV (eg, stigma or denial) were primary reasons why patients missed appointments. Development and dissemination of new tools and strategies, such as more formalized measurement of provision of retention services using quality-of-care indicators, may help increase delivery of recommended retention services.

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	Yes	No	Don't know
	▼	▼	▼
Practice routinely contacts patients prior to their appointments as a reminder (via mail, phone, or other)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 8
Practice routinely follows up on patients who miss their appointments (via mail, phone, or other)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 8
Practice provides patient navigation services (e.g., accompanying to appointments as needed)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 8
You or your practice routinely reinforces the value of follow-up visits	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 8
Practice has a program to systematically monitor retention in care of <i>all</i> HIV patients (e.g., monitoring visit adherence, gaps in care, or visits per interval of time)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 8

Figure 1. Questions about retention services provided to patients within provider’s practice, Medical Monitoring Project 2013–2014 Provider Survey. Do you agree with the following statements about services provided to patients at your practice?

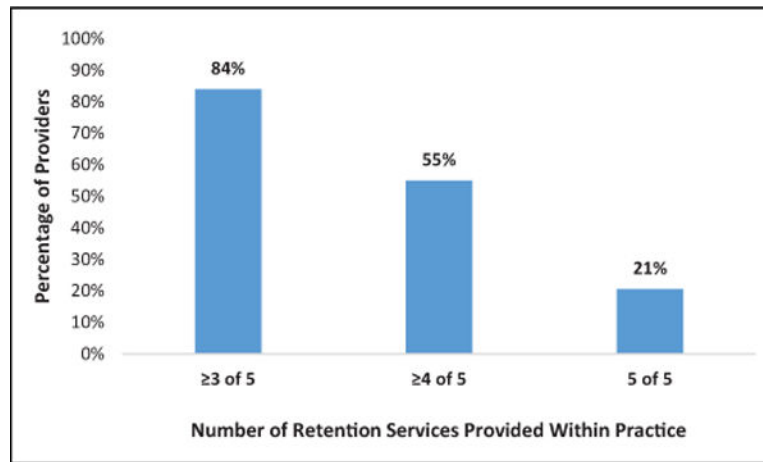


Figure 2. Percentage of HIV care providers whose practice offers at least 3 of 5, at least 4 of 5, and all 5 retention services, ^a Medical Monitoring Project 2013–2014 Provider Survey (N =1234). ^a Retention services included appointment reminders, missed visit follow-up, patient navigation services, reinforcing importance of follow-up visits, and systematic monitoring of retention in care.

Table 1

Estimated Provider and Practice Characteristics of HIV Adult Medical Care Providers in the United States—
Medical Monitoring Project 2013–2014 Provider Survey.^{a,b}

Demographics	n	wt %	95% CI
Age, years			
<40	211	17.5	12.9–22.2
40–49	326	24.0	21.2–26.8
50–59	453	38.4	32.3–44.6
60+	204	20.1	14.8–25.3
Gender			
Male	620	56.5	49.6–63.5
Female	585	43.5	36.5–50.4
Race/ethnicity			
Black/African American	89	10.8	3.8–17.7
Hispanic/Latino ^c	158	10.7	3.5–17.8
Other ^d	179	15.6	10.7–20.6
White	783	62.9	55.8–70.0
Qualifications and experience			
Certification type			
Non-board-certified physician ^e	61	4.8	2.2–7.4
ID board-certified physician ^e	564	44.5	37.3–51.7
Other board-certified physician ^e	319	30.0	22.8–37.3
Nurse practitioner	217	15.2	10.3–20.1
Physician assistant	63	5.4	2.6–8.2
HIV specialist ^f	865	57.8	51.2–64.4
Provides primary care ^g	1094	83.1	78.4–87.8
Practice characteristics			
Practice receives Ryan White HIV/AIDS Program funding	784	47.5	35.4–59.6
Private practice	300	41.9	33.3–50.6
Practice located in a large metropolitan area ^h	1001	68.7	60.3–77.1
Size of practice, number of HIV patients served			
Small: <50 patients	124	29.4	21.7–37.0
Medium: 50–400 patients	376	45.2	37.1–53.3
Large: >400 patients	734	25.4	20.4–30.5
Practice uses an electronic medical record	759	62.2	48.9–75.5
Practice uses an integrated team approach to HIV care ⁱ	874	54.0	45.6–62.6
Practice provides on-site case management	850	50.8	41.5–60.1

Abbreviations: CI, confidence interval; wt, weighted.

^aN = 1234.

^bNumbers=may not add to total and percentage may not total 100% because of missing data. Values exclude “don’t know” responses

^cHispanic or Latinos can be of any race. Providers are classified in only 1 race/ethnicity category.

^dIncludes American Indian/Alaska Native, Asian, Native Hawaiian/Other Pacific Islander, and multiple races.

^eDoctor of Medicine (MD) or Doctor of Osteopathic Medicine (DO).

^fAmerican Academy of HIV Medicine (AAHIVM) specialist certification (AAHIVS) detailed at <http://www.aahivm.org/aahivs>.

^gPoint of first contact, comprehensive care, emphasis on prevention and coordination of care.

^hBased on urban influence codes.

ⁱMultiple clinicians work together to augment the provider visit by providing previsit, postvisit, or between-visit contact with HIV-infected patients. Team members may include nurses, social workers, case managers, mental health providers, substance abuse counselors, and/or adherence counselors.

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Table 2

Percentage of HIV Care Providers Whose Practice Offers Retention-in-Care Services—Medical Monitoring Project 2013–2014 Provider Survey.^a

Type of Retention Service	n	wt. %	95% CI
Reinforcing importance of follow-up visits	1192	95.9	93.5–98.4
Appointment reminders	1071	88.6	85.5–91.7
Missed visit follow-up	961	82.1	78.2–86.1
Systematic monitoring of retention in care	767	53.4	43.8–63.1
Patient navigation services	486	33.1	26.5–39.6

Abbreviations: CI, confidence interval; wt, weighted.

^aN = 1234.

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Table 3
 Percentage of HIV Care Providers Whose Practice Offers All 5 Retention Practices, Patient Navigation Services, and Systematic Monitoring of Retention in Care Stratified by Practice Characteristics—Medical Monitoring Project 2013–2014 Provider Survey.^a

	All 5 Retention Services			Systematic Monitoring of Retention in Care			Patient Navigation Services		
	n	wt %	(95% CI)	n	wt %	(95% CI)	n	wt %	(95% CI)
Practice characteristics									
Practice receives Ryan White HIV/AIDS Program funding ^b									
Yes (n = 784)	239	33.6	26.2–41.0	575	77.0	69.1–84.9	364	44.7	37.3–52.2
No (n = 343)	36	8.6	4.2–12.9	131	31.0	22.3–39.6	77	23.3	13.3–33.3
Private practice ^b									
Yes (n = 300)	38	8.2	4.3–12.1	130	31.2	23.5–39.0	72	23.5	13.4–33.6
No (n = 934)	270	29.6	22.8–36.4	637	69.5	60.8–78.2	414	39.9	33.8–46.0
Practice located in a large metro area ^{c,d}									
Yes (n = 1001)	231	20.2	14.5–25.8	612	55.0	47.6–62.5	389	35.1	28.6–41.7
No (n = 233)	77	21.6	11.4–31.8	155	50.0	27.7–72.2	97	28.5	16.3–40.7
Size of practice, number of HIV patients served ^b									
Small: <50 patients (n = 124)	18	10.6	4.4–16.7	53	35.0	18.5–51.4	29	18.8	9.9–27.6
Medium: 50–400 patients (n = 376)	98	23.2	14.2–32.2	232	58.5	45.6–71.4	128	35.2	24.2–46.3
Large: >400 patients (n = 734)	192	27.6	22.4–32.8	482	65.8	60.8–70.9	329	45.6	41.0–50.3
Practice provides on-site case management ^b									
Yes (n = 850)	252	30.3	22.6–38.1	606	70.7	58.9–82.4	384	40.7	32.6–48.7
No (n = 384)	56	10.6	6.2–14.9	161	35.7	27.6–43.8	102	25.2	15.7–34.6

Abbreviations: CI, confidence interval; wt, weighted.

^aN = 1234.

^bSignificant Rao-Scott chi-square test result for all 3 outcomes at *P* .01.

^cNonsignificant Rao-Scott chi-square test result for all 3 outcomes at *P* .05.

^dPractice location based on urban influence codes.

Table 4

Percentage of HIV Care Providers Who Reported that Patients Often or Very Often Miss Scheduled Follow-up Visits Due to Specified Reasons—Medical Monitoring Project 2013–2014 Provider Survey.^a

	n	wt. %	(95% CI)
Mental health problems	618	40.5	35.8–45.2
Drug or alcohol abuse problems	567	36.1	30.3–41.9
Transportation problems	511	33.9	28.3–39.5
Emotional/psychological barriers related to HIV (e.g., stigma, denial, fear, or anger)	467	30.1	24.8–35.3
Reluctance to admit not following provider's advice	210	18.6	11.9–25.3
Homelessness	165	10.6	7.8–13.4
Childcare problems	138	8.4	5.7–11.1
Incarceration or legal detention	86	5.7	3.5–7.9
Too sick to travel to clinic	64	4.9	2.9–7.0

Abbreviations: CI, confidence interval; wt., weighted.

^aN =1234.

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