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Discrimination in healthcare settings among adults with recent HIV diagnoses

Amy R. Baugher, **Linda Beer**, **Jennifer L. Fagan**, **Christine L. Mattson**, and **for the Medical Monitoring Project**

Division of HIV/AIDS Prevention, Centers for Disease Control and Prevention, Atlanta, USA

Abstract

The prevalence of discrimination in healthcare settings among HIV patients in the United States is unknown. The Medical Monitoring Project (MMP) is a complex sample survey of adults receiving HIV medical care in the United States. We analyzed nationally representative MMP data collected 2011–2015. We assessed the prevalence of self-reported healthcare discrimination, perceived reasons for discrimination, and factors associated with discrimination among persons with HIV diagnoses ≤5 years before interview (n = 3,770). Overall, 14.1% of patients living with HIV (PLWH) experienced discrimination, of whom 82.2% attributed the discrimination to HIV. PLWH reporting poverty, homelessness, or attending a non-Ryan White HIV/AIDS Program (RWHAP) facility were more likely to report discrimination compared with other groups. Of patients attending non-RWHAP facilities, discrimination was higher among those in poverty (27.5%) vs. not in poverty (15.1%). Discrimination was associated with homelessness regardless of facility type, and was highest among homeless persons attending non-RWHAP facilities.

Healthcare discrimination was commonly reported among PLWH, and was most often attributed to HIV status. Discrimination was higher among those reporting poverty or homelessness, particularly those attending non-RWHAP facilities. Incorporating practices, such as antidiscrimination training, in facilities may reduce healthcare discrimination.

Keywords

Discrimination; HIV/AIDS; United States; Ryan White

Introduction

Discrimination occurs when a person experiences unfair treatment because they are perceived to be part of an undesirable group (NHAS, 2015). Discrimination in healthcare settings can be overt, such as refusing to treat a patient, or it can be subtle, such as not giving

CONTACT Amy R. Baugher YDA1@cdc.gov Division of HIV/AIDS Prevention, Centers for Disease Control and Prevention, 8 Corporate Blvd. Mailstop E-46, Atlanta, GA 30329, USA.

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Disclaimer

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a patient equitable care (Schuster et al., 2005). In the 1990s, 26% of patients with HIV receiving care in the U.S. reported discrimination in healthcare settings after their HIV diagnosis. Reducing discrimination is a national HIV prevention goal (HIV.gov, n.d.).

In healthcare settings, adults with diagnosed HIV who are in care (hereafter referred to as "patients living with HIV" or "PLWH") have described situations where providers seemed afraid of them, discouraged them, or treated them differently (Zukoski & Thorburn, 2009). Discrimination has been reported across a range of clinical settings and types of clinic staff (Schuster et al., 2005; Zukoski & Thorburn, 2009). Studies suggest that discrimination discourages some PLWH from attending HIV provider visits or adhering to HIV medicines (Schuster et al., 2005), which is critical for achieving viral suppression (Cohen et al., 2011).

National estimates for the prevalence of healthcare discrimination among PLWH in U.S. healthcare settings were last reported during the mid-1990s by the HIV Cost and Services Utilization Study (HCSUS) (Schuster et al., 2005). Recent estimates are needed. There is also limited information on the perceived reasons for discrimination in healthcare settings (Schuster et al., 2005), which could help inform discrimination-reduction interventions.

The objectives of this analysis were to describe the prevalence of self-reported discrimination in healthcare settings among PLWH with recent diagnoses, and the behavioral, clinical, and facility characteristics associated with discrimination.

Materials and methods

Medical monitoring project

The Medical Monitoring Project (MMP) is an HIV surveillance system designed to produce nationally representative estimates of behavioral and clinical characteristics of adults receiving HIV care in the U.S using interview and medical record data (Bradley et al., 2015; Iachan et al., 2016). For the 2011–2014 cycles, MMP used a 3-stage, probability-proportional-to-size sampling method, which sampled states and one territory, then outpatient facilities providing HIV care, and finally PLWH ≥18 years old who reported ≥1 medical care visit(s) in a participating facility during January–April of each cycle year. This analysis used pooled, cross-sectional data from June 2011–May 2015. We also examined data on the characteristics of the HIV care facilities where respondents were sampled.

All sampled states and territories participated in MMP. Facility response rates ranged from 83–86% and patient response rates ranged from 49–56%. Data were weighted to account for unequal selection probabilities and both facility and patient non-response.

Measures

To measure discrimination, we asked respondents if, after receiving an HIV diagnosis, anyone in the healthcare system: (1) exhibited hostility or a lack of respect towards them, (2) gave them less attention than other patients, or (3) refused them service. Discrimination was defined as reporting at least one discriminatory experience in a healthcare setting since HIV diagnosis. Respondents reporting discrimination indicated the personal characteristics to

which they attributed the discrimination: HIV status, gender identity, sexual orientation, race/ethnicity, and injection drug use.

Analytic methods

We analyzed the prevalence of any healthcare discrimination since HIV diagnosis among all persons receiving HIV medical care (n = 19,466), and then among PLWH diagnosed ≤5 years before interview date (n = 3,770). We restricted to persons with recent diagnoses to measure discrimination that occurred relatively recently, since patients receiving care in the early decades of the HIV epidemic likely had different experiences of discrimination (Herek, Capitanio, & Widaman, 2002).

Among persons with recent diagnoses, we next present the prevalence of the characteristics to which they attributed the perceived discrimination. We then assessed differences in discrimination by sociodemographic, behavioral, clinical, and facility characteristics using bivariate Rao-Scott chi-square tests.

We assessed whether attending a facility funded by the Ryan White HIV/AIDS Program (RWHAP) was an effect modifier of the relationship between discrimination and socioeconomic factors, specifically poverty and homelessness, since anti-discrimination is a core value of RWHAP (HRSA, n.d.).

The Centers for Disease Control and Prevention (CDC) determined MMP was public health surveillance used for disease control, program, or policy purposes (CDC, 2010). Local institutional review board approval was obtained at participating project areas and facilities when required. Informed consent was obtained from all interviewed participants.

Results

Among all PLWH in care, 22.8% (95% CI 21.1, 24.5) reported any discrimination in healthcare settings since diagnosis (data not shown in tables). Among PLWH in care with recent diagnoses, 14.1% reported any discrimination. Among PLWH reporting discrimination (n = 503), 82.2% attributed discrimination to their HIV status and 32.1% to their sexual orientation (Table 1). Among PLWH with recent diagnoses, discrimination was significantly more common among those who experienced poverty in the past 12 months, reported homelessness in the past 12 months, or received care from a non-RWHAP-funded facility (Table 2).

Among patients receiving care at RWHAP-funded facilities (Table 3), there was no significant difference in discrimination between patients experiencing poverty (14.9%) vs. not experiencing poverty (12.5%; odds ratio [OR]: 1.2). However, among patients attending non-RWHAP facilities, those experiencing poverty (27.5%) had higher odds of reporting discrimination than patients not experiencing poverty (15.1%, OR: 2.1). Homelessness was associated with higher odds of discrimination among persons who attended RWHAP facilities (21.5% homeless vs. 12.3% non-homeless) and non-RWHAP facilities (34.0% homeless vs. 17.0% non-homeless), but there was a slightly stronger effect among persons attending non-RWHAP facilities (RWHAP OR: 1.9 vs. non-RWHAP OR: 2.5).

Discussion

More than 1 in 8 recently diagnosed PLWH receiving medical care reported discrimination in healthcare settings, most of whom attributed the discrimination to their HIV status. This updated estimate is lower than the 26% prevalence of discrimination among PLWH in care reported by HCSUS in the mid-1990s (Schuster et al., 2005), but the population is limited to PLWH who were recently diagnosed.

Healthcare discrimination was higher among those living in poverty, but only among those attending non-RWHAP facilities. Higher discrimination was reported among homeless patients regardless of facility type. Patients attending RWHAP facilities are more likely to have better health outcomes compared with patients attending non-RWHAP facilities (Bradley et al., 2016; Weiser et al., 2015). Lower levels of discrimination at RWHAP clinics may play a role in better health outcomes, which could be explored in future studies.

RWHAP facilities use a medical home model, offering comprehensive, patient-centered care, which reduces staff burnout, wait times, and increases patient satisfaction (Beane, Culyba, DeMayo, & Armstrong, 2014; Valverde et al., 2004). RWHAP facilities utilize a multi-disciplinary approach, where care, case management, and support services are integrated and patient-provider relationships are emphasized (Beane et al., 2014). These factors may contribute to lower perceptions of discrimination in RWHAP facilities.

RWHAP facilities serve low-income PLWH and incorporate anti-discrimination and cultural competency in staff training (HRSA). RWHAP funds the AIDS Education and Training Centers (AETCs), which provide HIV education and training for providers and clinic staff (Johnson, 2011). AETC programs have reduced HIV stigma among clinic staff (Mulligan, Seirawan, Galligan, & Lemme, 2006). Further, quality improvement activities, which hold programs to the same standards, are required of RWHAP-funded programs (Agins, 2014). It is possible that RWHAP trainings and quality requirements contribute to lower discrimination. Non-RWHAP facilities may benefit from similar anti-discrimination trainings and quality improvement activities.

Limitations and strengths

There were limitations to this analysis. Discrimination data were based on perceptions rather than objective measurements; however, research has linked perceptions of discrimination to poor health outcomes (Schuster et al., 2005). Second, this analysis is restricted to persons receiving care, but discrimination in a healthcare setting could be related to dropping out of care. Since discrimination could have occurred at any point since diagnosis, we cannot assess temporality. Lastly, we do not have information about whether discrimination occurred at the facility from which the person was sampled. However, 99.7% of respondents reported attending one HIV care facility in the past 12 months. Therefore, it is reasonable to assume the discrimination occurred at their usual care facility.

Despite these limitations, strengths of this analysis include the probability-based sampling, which allowed us to provide nationally representative estimates and a large, geographically diverse sample.

It is important that all PLWH are in care and adherent to HIV medicines, yet discrimination could potentially dissuade persons from seeking care (Kinsler, Wong, Sayles, Davis, & Cunningham, 2007). Because persons attending RWHAP-funded facilities report less discrimination, facilities may consider adopting characteristics of RWHAP facilities (e.g., emphasizing comprehensive care and anti-discrimination training for providers and staff) to help reduce discrimination. All facilities may benefit from additional trainings on working with patients experiencing homelessness. Facilities may consider reviewing their practices to ensure all patients are treated equally and with respect.

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Table 1.

Discrimination in healthcare settings experienced by adults living with HIV in care with recent diagnoses, Medical Monitoring Project 2011–2014 (n = 3,770).

Question	n	Weighted % (95% CI)
Has anyone in the healthcare system done any of the following to you since testing positive for HIV?		
Exhibited hostility or a lack of respect towards you?	428	12.0 (10.9, 13.2)
Given you less attention than other patients?	289	8.4 (7.3, 9.5)
Refused you service?	129	3.6 (3.0, 4.2)
Reported any discrimination[a]	503	14.1 (12.8, 15.5)
Did the discrimination occur because of your … ?[b]		
Characteristic	n	Weighted % attributed discrimination to characteristic (95% CI)
HIV status	383	82.2 (77.9, 86.6)
Gender	58	10.8 (7.7, 13.8)
Sexual orientation	148	32.1 (25.9, 38.3)
Race/ethnicity	66	12.5 (9.6, 15.3)
Injection drug use	22	4.7 (2.2, 7.2)

[a]Respondent experienced hostility or a lack of respect, was given less attention, or was refused service at a healthcare facility since testing positive for HIV.

[b]Respondent could select more than one option.

Table 2.

Sociodemographic, behavioral, clinical, and facility characteristics of adults living with HIV in care with recent diagnoses reporting any discrimination, Medical Monitoring Project 2011–2014 (n = 3,770).

Variable	*n*	Any discrimination	Weighted % (95% CI)	No discrimination	Weighted % (95% CI)	*p*-value
Gender						
Male	2838	373	14.0 (12.3, 15.8)	2465	86.0 (84.2, 87.7)	0.08
Female	877	118	13.8 (11.7, 16.0)	759	86.2 (84.0, 88.3)	Ref
Transgender[a]	53	12	24.5 (11.7, 37.4)	41	75.5 (62.6, 88.3)	0.05
Race/ethnicity						
Black	1746	184	11.5 (9.6, 13.4)	1562	88.5 (86.6, 90.4)	Ref
Hispanic/Latino[b]	912	126	13.3 (11.0, 15.7)	786	86.7 (84.3, 89.0)	0.05
White	913	153	18.2 (15.1, 21.2)	760	81.8 (78.8, 84.9)	0.09
Otder/Multiracial[c]	199	40	21.3 (15.1, 27.5)	159	78.7 (72.5, 84.9)	0.02
Age (years)						
18–29	973	127	14.0 (11.1, 16.9)	846	86.0 (83.1, 88.9)	0.95
30–39	952	134	14.7 (12.3, 17.2)	818	85.3 (82.8, 87.7)	0.57
40–49	963	133	15.0 (12.5, 17.6)	830	85.0 (82.4, 87.5)	0.37
≥50	882	109	12.7 (10.3, 15.1)	773	87.3 (84.9, 90.0)	Ref
Sexual orientation						
Homosexual	1195	173	15.3 (12.7, 17.9)	1022	84.7 (82.1, 87.3)	0.55
Heterosexual	1297	167	13.4 (11.4, 15.5)	1130	86.6 (84.5, 88.6)	Ref
Bisexual	270	39	15.3 (10.7, 19.9)	231	84.7 (80.1, 89.3)	0.69
Education						
< *High school*	711	79	11.6 (8.2, 15.1)	632	88.4 (84.9, 91.8)	Ref
High school or equivalent	1108	127	12.9 (10.4, 15.3)	981	87.1 (84.7, 89.6)	0.58
> *High school*	1950	297	15.7 (14.3, 17.2)	1653	84.3 (82.8, 85.8)	0.04
Poverty[d] in past 12 months						
Above poverty level	1736	216	13.4 (11.5, 15.3)	1520	86.6 (84.7, 88.5)	Ref
At or below poverty level	1814	268	15.6 (13.8, 17.4)	1546	84.4 (82.6, 86.2)	0.04
Homelessness[e]						
Homeless in past 12 months	421	88	22.4 (16.9, 27.9)	333	77.6 (72.1, 83.1)	<0.01
Not homeless in past 12 months	3349	415	13.1 (11.7, 14.6)	2934	86.9 (85.4, 88.3)	Ref
Incarcerated in past 12 months						
Yes	223	39	18.7 (13.4, 24.0)	184	81.3 (76.0, 86.6)	0.05
No	3546	463	13.8 (12.4, 15.3)	3083	86.2 (84.7, 87.6)	Ref
Country of birth						
Born outside U.S.	666	73	11.1 (6.7, 13.4)	593	88.9 (86.6, 91.3)	Ref
Born in U.S.	3103	430	14.8 (13.2, 16.3)	2673	85.2 (83.7, 86.8)	0.01
Injection drug use						
Injected drugs in past 12 months	84	18	25.1 (12.0, 38.1)	66	74.9 (61.9, 88.0)	0.04

Variable	*n*	Any discrimination	Weighted % (95% CI)	No discrimination	Weighted % (95% CI)	*p*-value
Did not inject drugs in past 12 months	3675	481	13.8 (12.5, 15.2)	3194	86.2 (84.8, 87.5)	Ref
ART use and adherence[f]						
Not taking ART	343	40	13.8 (9.9, 17.8)	303	86.2 (82.2, 90.1)	0.97
Taking ART, Not Adherent	400	53	13.2 (9.8, 16.6)	347	86.8 (83.4, 90.2)	Ref
Taking ART, Adherent	2927	395	14.3 (12.8, 15.8)	2532	85.7 (84.2, 87.2)	0.58
Sustained viral suppression in past 12 months[g]						
All viral loads <200 copies/ml	2152	293	14.4 (12.7, 16.2)	1859	85.6 (83.8, 87.3)	0.59
≥1 viral loads ≥200 copies/ml	1618	210	13.8 (11.9, 15.6)	1408	86.2 (84.4, 88.1)	Ref
Clinical status						
AIDS or CD4⁺ cell count 0–199 cells/μl (nadir)	1914	250	14.0 (12.0, 16.0)	1664	86.0 (84.0, 88.0)	0.08
No AIDS and CD4⁺ cell count 200–499 cells/μl (nadir)	1431	192	13.7 (11.7, 15.7)	1239	88.3 (84.3, 88.3)	Ref
No AIDS and CD4⁺ cell count ≥500 cells/μl (nadir)	402	60	17.2 (13.0, 21.3)	342	82.8 (78.7, 87.0)	0.42
Ryan White HIV/AIDS Program (RWHAP) funded facility[h]						
Yes	2877	359	13.4 (12.1, 14.8)	2518	86.6 (85.2, 87.9)	Ref
No	643	115	18.3 (13.6, 23.0)	528	81.7 (77.0, 86.4)	0.03
Facility type[i]						
Public	1435	180	13.5 (11.2, 15.8)	1255	86.5 (84.2, 88.8)	Ref
Private	2151	295	14.5 (12.9, 16.1)	1856	85.5 (83.9, 87.1)	0.53
Other	115	21	17.7 (11.4, 24.0)	94	82.3 (76.0, 88.6)	0.21
Facility size[j]						
Small	158	23	15.5 (8.0, 23.1)	135	84.5 (76.9, 92.0)	0.72
Medium	1386	194	14.5 (12.1, 17.0)	1192	85.5 (83.0, 87.9)	0.97
Large	2226	286	13.8 (12.3, 15.3)	1940	86.2 (84.7, 87.7)	Ref
Single pace of care in past 12 months	3758	501	14.1 (12.8, 15.5)	3257	85.9 (84.5, 87.2)	0.20

[a]Patients were classified as transgender if sex at birth and gender reported by patient were different, or if patient chose transgender in response to the question about self-identified gender.

[b]Hispanic/Latinos might be of any race. Patients are classified in only one race/ethnicity category.

[c]Persons who reported multiple racial identities or a race/ethnicity other than non-Hispanic white, non-Hispanic black, or Hispanic/Latino were categorized as “other/multiracial.”

[d]Poverty guidelines as defined by the Department of Health and Human Services (HHS). More information regarding the HHS poverty guidelines can be found at http://aspe.hhs.gov/poverty/faq.cfm.

[e]Living on the street, in a shelter, in a single-room-occupancy hotel, or in a car.

[f]Antiretroviral therapy (ART) use and adherence were defined as a three-level categorical variable: not taking ART; taking ART, but not adherent; and taking ART, adherent. Adherence was defined as self-reported 100% adherence to all HIV medicine doses in the past 3 days.

[g]Sustained viral suppression was defined as all HIV viral load tests documented as undetectable or <200 copies/mL during the past 12 months.

[h] Ryan White HIV/AIDS Program (RWHAP) funding was defined as receiving any funding from any Ryan White source, including parts A, B, C, or D.

[i] Facility type was categorized as public-owned, private-owned, or other type of ownership.

[j] Facility size was categorized as small (<50 patients), medium (50–400 patients), and large (>400 patients).

Table 3

Percentage of adults living with HIV with recent diagnoses reporting discrimination[a] stratified by poverty[b], homelessness[c], and attending a facility funded by Ryan White HIV/AIDS Program (RWHAP)[d], Medical Monitoring Project 2011–2014.

	Discrimination					
	Yes		No			
	n	%	n	%	Odds Ratio	95% CI
RWHAP						
Poverty in past 12 months					1.2	0.9, 1.5
Yes	213	14.9 (13.0, 16.8)	1312	85.1 (83.2, 87.0)		
No	132	12.5 (10.4, 14.5)	1042	87.5 (10.4, 14.5)		
Homelessness in past 12 months					1.9	1.3, 2.9*
Yes	68	21.5 (15.0, 27.9)	280	78.5 (72.1, 85.0)		
No	291	12.3 (11.0, 13.7)	2238	87.7 (86.4, 89.0)		
Non-RWHAP						
Poverty in past 12 months					2.1	1.3, 3.5*
Yes	42	27.5 (18.0, 36.9)	124	72.5 (63.1, 82.0)		
No	69	15.1 (10.5, 19.7)	384	84.9 (80.3, 89.5)		
Homelessness in past 12 months					2.5	1.4, 4.6*
Yes	17	34.0 (20.7, 47.2)	32	66.0 (52.8, 79.3)		
No	98	17.0 (12.3, 21.6)	496	83.0 (78.4, 87.7)		

*$p < 0.05$.

[a]Discrimination was defined as reporting at least one discriminatory experience in an HIV healthcare setting: exhibited hostility or a lack of respect towards you to given you less attention than other patients, or refused you service.

[b]Poverty guidelines as defined by the Department of Health and Human Services (HHS). More information regarding the HHS poverty guidelines can be found at http://aspe.hhs.gov/poverty/faq.cfm.

[c]Living on the street, in a shelter, in a single-room-occupancy hotel, or in a car.

[d]Ryan White HIV/AIDS Program (RWHAP) was defined as a facility receiving any Ryan White funding from any Ryan White source.