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Changes in Perceived Discrimination in Healthcare Settings Reported by HIV Patients in the United States from 1996 to 2011–2013

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Background

Discrimination in healthcare settings is a barrier to healthcare engagement, which for HIV patients is essential for reducing morbidity, mortality, and the likelihood of HIV transmission. The most recent published United States national estimates of discrimination in healthcare settings reported by HIV patients are from 1996, when 26% of HIV patients in care reported such experiences of discrimination.¹ These discriminatory experiences were negatively associated with access to care, quality ratings of medical and hospital care, and trust in doctors or clinics.¹ We analyzed two nationally representative datasets to assess change in discrimination in healthcare settings reported by HIV patients from 1996 to 2011–2013.

Methods

The HIV Cost and Services Utilization Study (HCSUS) and the Medical Monitoring Project (MMP) used similar probability sampling methods to generate national estimates of the characteristics of HIV-positive adults receiving medical care in the United States. Briefly, both projects recruited participants from population-based samples of outpatient HIV care facilities and collected data via in-person or telephone interviews with a matched medical record abstraction.^{2, 3} The facility response rate was 81% in HCSUS and 85% in 2013 for the MMP; the patient response rate was 71% in HCSUS and 55% in 2013 for the MMP. Both projects measured perceived discrimination in healthcare settings based on a positive response to any component of the interview question: “*Has anyone in the healthcare system ever done any of the following to you since testing positive for HIV? a. Exhibited hostility or a lack of respect toward you; b. Given you less attention than to other patients; c. Refused you service*”. An affirmative answer to the follow-up question: “*Did the discrimination occur because of your HIV infection?*” measured whether the perceived discrimination occurred because of the patient’s HIV status.

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All HCSUS participants were included in the analysis but MMP participants were restricted to those participating in the 2011–2013 cycles. Analyses incorporated the surveys' respective complex sample designs, unequal selection probabilities, and differential nonresponse to calculate weighted prevalence estimates. We assessed significant differences in reported discrimination between the time-periods, overall and within subgroups, via linear contrasts. These incorporate pooled variance estimates for the combined survey data sets and t-tests of the null hypothesis of no difference using the conventional threshold of 0.05 and two-sided tests of differences.

HCSUS received approval from the RAND Corporation's IRB.² As public health surveillance; MMP was exempt from IRB review. Informed consent was obtained from all participants in both projects.

Results

HCSUS patients were 77% male, 33% African American, with a mean age of 39 years, and mean time since HIV diagnosis of 5 years; while MMP patients were 74% male, 42% African American, with a mean age of 47 years, and mean time since HIV diagnosis of 7 years. Overall, perceived discrimination in healthcare settings reported by HIV patients significantly decreased over time, from 24% in 1996 to 15% in 2011–2013 (9% point decrease, 95% confidence interval –6,–12). Significant decreases were observed among all groups except among persons: ≥ 50 years of age, with a CD4 cell count of 500 cells per mm³ or higher, or persons of "other" (i.e., Asian American, American Indian/Alaskan Native, multiracial, or Native Hawaiian/Pacific Islander) race/ethnicity. (Table 1).

Discussion

Between 1996 and 2011–2013, perceived discrimination in healthcare settings reported by HIV patients declined significantly, overall and among most sub-groups. Improvements over time in HIV clinicians' engagement in HIV prevention discussions with patients following recommendations made in 2003 by the Centers for Disease Control and Prevention, the Health Resources Services Administration, the National Institutes of Health and the HIV Medical Association incorporating HIV prevention into the medical care of persons living with HIV,⁴ may have played a large part in reducing communication barriers between clinicians and patients, which in turn may have reduced patients' perceptions that HIV clinicians engaged in actions that patients perceived discriminatory. Additionally, changes in public acceptance of social issues affecting some populations heavily impacted by HIV⁵ may have also been a contributing factor.

Although the observed decrease suggests progress, 15% of HIV patients still perceive discrimination in their care, which indicates room for improvement. Furthermore, significant declines were not observed among certain groups, including persons ≥ 50 years of age, who account for 48% of persons with diagnosed HIV infection in the United States.⁶ Ensuring that all HIV-positive persons receive care in settings free from discrimination may require a better understanding of the healthcare settings in which discriminatory practices occur and enhanced communication training for clinicians and staff.

This analysis is subject to several limitations. First, because HCSUS and MMP response rates were lower than optimal, our discrimination measures may be subject to some measurement error. However, both surveys had information on all sampled facilities and patients and were able to assess factors associated with non-response.^{3,7} This information was used to adjust the estimates to reduce non-response bias using standard methods,⁸ which follows recommendations from the Office of Management and Budget's (OMB) Standards and Guidelines for Statistical Surveys. The stratified results may be less subject to bias, since they would not be affected by any differential response among the examined groups. The fact that almost all stratified estimates indicate a decrease supports the finding of an overall decrease in discrimination. Second, some residual measurement error may exist due to self-report of discrimination. Finally, combining the HCSUS and MMP datasets to determine statistically significant differences assumes equivalent survey methods, which may overstate the actual significance level by underestimating the variance.

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Dr. Eduardo Valverde had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis

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Table 1.

Changes in reported perceived healthcare discrimination attributed to one's HIV status, by selected characteristics—United States, 1996–2011/2013

	U.S. HIV patients, 1996 (HCSUS)			U.S. HIV patients*, 2011-2013 (MMP)			% point change	95% Confidence Intervals	P-Value
	N (%)	Weighted %	95% Confidence Intervals	N (%)	Weighted %	95% Confidence Intervals			
Total	2859	24	22, 27	8494	15	13, 16	-9	-12, -6	P < .001
Gender	2014	24	22, 27	6126	14	12, 16	-10	-14, -7	P < .001
Male	845	23	19, 27	2364	17	15, 19	-6	-10, -1	P = 0.01
Female									
Age (years)	985	25	22, 28	1918	14	12, 16	-11	-15, -7	P < .001
18–34	1588	25	21, 29	3643	16	14, 18	-9	-13, -5	P < .001
35–49	286	18	13, 24	2903	14	12, 16	-4	-10, 2	P = 0.16
50 or older									
Race/ethnicity**	955	16	13, 20	3847	11	10, 13	-5	-8, -1	P = 0.01
African American	415	21	16, 26	1941	14	12, 16	-7	-12, -1	P = 0.01
Hispanic/Latino	91	19	11, 30	377	22	18, 26	+3	-6, 14	P = 0.47
Other***	1398	31	27, 34	2329	19	17, 22	-12	-15, -7	P < .001
White									
Sexual behavior/orient****	1368	26	23, 29	3894	15	13, 17	-11	-14, -7	P < .001
MSM	532	21	17, 26	2071	11	9, 14	-10	-15, -4	P < .001
MSW	741	23	18, 28	2310	17	15, 19	-6	-10, -1	P = 0.03
WSM									
Education	721	18	14, 22	1851	13	11, 14	-5	-9, -1	P = 0.01
Less than high school	804	25	22, 28	2346	12	10, 14	-13	-17, -9	P < .001
(HS)	808	27	23, 31	4290	17	15, 19	-10	-14, -5	P < .001
HS degree									
More than HS									
Insurance	951	24	21, 27	2351	16	13, 18	-8	-12, -5	P < .001
Private	1637	26	23, 29	4149	17	14, 19	-9	-12, -5	P < .001
Public	267	17	14, 21	1800	10	8, 12	-7	-12, -2	P = 0.01
No insurance									
CD4 count per mm3	659	27	25, 30	299	16	11, 21	-11	-14, -5	P < .001
0–49	853	26	23, 29	853	13	10, 15	-13	-17, -9	P < .001
50–199	1094	21	18, 24	3467	14	12, 16	-7	-10, -3	P < .001
200–499	253	22	15, 31	3428	16	14, 18	-6	-14, 1	P = 0.10
500 or higher									

* Infection diagnosed after 1996.

** Based on self-reported information on race/ethnicity from questions based on the Office of Management and Budget (OMB) DIRECTIVE NO. 15 Race and Ethnic Standards for Federal Statistics and Administrative Reporting.

*** Asian American, American Indian/Alaskan Native, multiracial, or Native Hawaiian/Pacific Islander race/ethnicity.

**** Based on self-reported information on sexual behaviors for sexually-active persons (past 12 months for MMP, past 6 months for HCSUS), sexual orientation was used for celibate persons: MSM (men who had sex with men, gay/bisexual orientation for celibate men); MSW (man who only had sex with women, heterosexual orientation for celibate men); WSM (women who had sex with men, heterosexual orientation for celibate women).