



HIV/AIDS Factsheet: HIV-Related Stigma and Its Association with Health Outcomes Among Persons Living With HIV/AIDS in Illinois

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Introduction

HIV-related stigma has been defined as discounting, discrediting, and discriminating against people perceived to have HIV [1,2]. There is a growing body of literature exploring stigma and health for people living with HIV [3], suggesting that HIV-infected persons experience significant HIV-related stigma [4] and one of the biggest challenges facing people living with HIV today is stigma [5].

Stigma negatively affects people living with HIV. A recent review of the qualitative evidence showed that HIV-related stigma is a broad social phenomenon that manifests within multiple social spheres, including health care environments, and can influence health care utilization, treatment adherence, and overall health and well-being of people living with HIV [3].

Reducing stigma is an objective of the National HIV/AIDS Strategy (NHAS) [6]. In order to better understand HIV-related stigma and meet the NHAS goal, this analysis aims to: 1) assess the prevalence of HIV-related stigma among HIV-infected persons in Illinois; 2) examine HIV-related stigma by different socio-demographic groups; and 3) evaluate the relationship between HIV-related stigma and intermediate health-related outcomes, such as adherence to antiretroviral medications, viral load suppression, depression, and anxiety.

Methods

This analysis used data collected in the 2015-2017 combined three-year cycle of the Medical Monitoring Project (MMP). MMP is a surveillance system designed to understand the experiences and needs of people living with HIV. It is supported by several government agencies and conducted by state and local health departments, along with the Centers for Disease Control and Prevention (CDC). Detailed MMP methods, including weighting procedures, have been described elsewhere [7]. In brief, MMP is an annual cross-sectional survey of a population-based sample of HIV-infected adults. It adopts a two-stage sampling method to produce nationally and locally representative estimates of adults with diagnosed HIV infection. Data collection includes face-to-face or telephone interviews and medical record abstraction. Data are weighted to represent all adults with diagnosed HIV infection.

MMP measures HIV-related stigma using an abbreviated 10-item scale during in-person or telephone interviews (as shown in Table 1). For each statement (item), one of five graded responses (raw score) is recorded: Strongly disagree (raw score =1), Somewhat disagree (raw score =2), Neutral (raw score =3), Somewhat agree (raw score =4), Strongly agree (raw score =5). CDC provided Illinois with combined data for the 2015, 2016, and 2017 cycles. A calculated variable for summary stigma score is obtained using the formula $(\text{raw score} - 1) \times 2.5$, the corresponding score for an answer to each item would be either 0, 2.5, 5, 7.5, or 10, respectively. Thus, for a total of 10 items, summary stigma score ranges from 0-100, with a high score indicating a greater level stigma.

All analyses were adjusted for the sample design using SAS Proc SurveyFreq or SurveyMeans. SAS for Windows 9.4 was used for all analyses.

Results

A total of 709 cases were included in the 2015-2017 combined three-year cycle of MMP, representing a weighted prevalence of 35,633 persons living with HIV/AIDS in Illinois (all results shown in this analysis are weighted numbers). The distribution of responses to the 10-item stigma scale questions among diagnosed HIV-infected adults is shown in Table 1.

Table 1. Distribution of responses to stigma questions among diagnosed HIV-infected persons in Illinois, 2015-2017 MMP

Question	(1)Strongly disagree		(2)Somewhat disagree		(3)Neutral		(4)Somewhat agree		(5)Strongly agree		Total*
	N	%	N	%	N	%	N	%	N	%	
I have been hurt by how people reacted to learning I have HIV.	12,924	37.39	2,611	7.55	4,916	14.22	5,230	15.13	8,889	25.71	34,569
I have stopped socializing with some people because of their reactions to my HIV status.	18,038	52.39	2,216	6.44	3,962	11.51	3,160	9.18	7,055	20.49	34,430
I have lost friends by telling them I have HIV.	20,088	58.35	2,640	7.67	3,254	9.45	2,917	8.47	5,526	16.05	34,425
I am very careful who I tell that I have HIV.	2,961	8.46	841	2.40	1,013	2.89	3,414	9.75	26,779	76.50	35,007
I worry that people who know I have HIV will tell others.	8,644	24.75	2,397	6.86	2,419	6.93	5,339	15.29	16,120	46.16	34,918
I feel that I am not as good a person as others because I have HIV.	24,452	69.94	1,570	4.49	1,348	3.86	4,342	12.42	3,247	9.29	34,960
Having HIV makes me feel unclean.	22,897	65.34	2,831	8.08	1,941	5.54	3,890	11.10	3,485	9.95	35,043
Having HIV makes me feel that I'm a bad person.	28,589	81.58	1,603	4.57	1,095	3.13	2,271	6.48	1,485	4.24	35,043
Most people think that a person with HIV is disgusting.	12,202	35.05	2,616	7.51	4,225	12.14	8,054	23.13	7,717	22.17	34,814
Most people with HIV are rejected when others find out.	5,643	16.25	3,791	10.92	4,580	13.19	9,744	28.05	10,974	31.60	34,733

* Totals may be different because of missing answers.

Data in Table 1 suggests that while certain dimensions of HIV-related stigma are experienced among HIV-infected persons, the magnitude depends on the questions asked. More than 76% strongly agree that they are very careful who they tell that they have HIV, and close to half (46%) strongly agree that they worry that people who know their HIV status will tell others.

As shown in Table 2, there was a significant gender difference in HIV-related stigma; females had a higher stigma score than males (53.1 vs 39.5; $p < 0.001$). Non-Hispanic Blacks and Latinos experienced greater HIV-related stigma as compared to non-Hispanic Whites (45.8, 52.0 vs 41.3, respectively; $p < 0.01$). Persons living with HIV/AIDS who had a post-secondary education, were living above the federal poverty level, and were not homeless experienced less HIV-related stigma as compared to those with less than a high school education (38.6 vs 41.5; $p = 0.04$), living below the poverty line (37.4 vs 42.0; $p = 0.016$), and that were homeless (39.6 vs 44.6; $p = 0.007$). Persons with public insurance only (excluding Ryan White HIV/AIDS Program [RW] and AIDS Drug Assistance Program [ADAP] only) were shown to have higher HIV-related stigma score than those with private insurance (42.3 vs 36.0; $p = 0.003$). There were slight variations in stigma score among different age groups, but the differences were not statistically significant.

Table 3 lists HIV-related stigma score by clinical and health characteristics. This analysis did not find any association between HIV-related stigma and time since HIV diagnosis (<1 year vs ≥ 1 year), viral load in the last 12 months (<200 copies/ml vs ≥ 200 copies/ml or missing), alcohol use in the past 30 days, or drug use in the past 12 months (injection or non-injection). HIV-infected persons currently not taking antiretroviral therapy (ART) had higher HIV-related stigma score than those currently taking ART, and the difference achieved borderline statistical significance (41.3 vs 39.8; $p = 0.066$). Persons living with HIV/AIDS with at least one unmet need had a larger HIV-related stigma score than those without any unmet need (48.6 vs 35.2; $p < 0.001$). The unmet need for persons living with HIV/AIDS refers to those who are aware of their HIV infection and who have not received any HIV-related primary care within the past 12 months (at least one CD4 or viral load or HIV-1 genotype test were considered as having received HIV care). Those with major depression or other depression as compared to no depression (50.0, 59.3 vs 39.2; $p = 0.002$, $p < 0.001$, respectively), or those with mild, moderate, or severe anxiety as compared to no anxiety (49.9, 50.7, 64.4 vs 38.3; $p = 0.004$, $p = 0.001$, $p < 0.001$, respectively), also had higher HIV-related stigma score.

Table 2. Mean stigma score by socio-demographic among diagnosed HIV-infected persons in Illinois, 2015-2017 MMP

		Weighted N	%	Mean	95% CI		p value
Gender	Male	28,043	78.70	39.51	37.47	41.56	Ref
	Female	7,287	20.45	53.12	48.67	57.58	<0.001
	Transgender	304	0.85	45.90	30.85	60.94	0.410
Race/ethnicity	White, non-Hispanic	10,808	30.33	37.95	34.60	41.30	Ref
	Black, non-Hispanic	17,746	49.80	43.18	40.56	45.80	0.016
	Hispanic or Latino	5,471	15.35	46.90	41.82	51.97	0.004
	Other	1,608	4.51	46.63	35.62	57.64	0.139
Age (years)	18-24	1,461	4.10	44.30	33.39	55.20	Ref
	25-34	5,287	14.84	44.40	39.88	48.92	0.986
	35-44	7,156	20.08	42.48	38.50	46.46	0.759
	45-54	11,558	32.44	40.84	37.58	44.10	0.552
	≥55	10,171	28.54	42.22	38.17	46.27	0.727
Education	<High school	5,064	14.25	46.21	41.53	50.89	Ref
	High school diploma or equivalent	6,859	19.30	44.43	39.05	49.81	0.624
	>High school	23,617	66.45	40.82	38.59	43.04	0.041
Poverty	Above poverty level	18,819	54.94	40.06	37.39	42.73	Ref
	At or below poverty level	15,437	45.06	44.96	42.01	47.92	0.016
Homeless	No, not homeless	32,922	92.63	41.54	39.55	43.53	Ref
	Yes, was homeless	2,618	7.37	51.72	44.62	58.82	0.007
Insurance	Any private insurance	14,427	40.80	38.92	36.00	41.83	Ref
	Public insurance only (excluding RW/ADAP only)	18,822	53.23	45.00	42.28	47.72	0.003
	RW/ADAP only	1,703	4.82	37.77	31.34	44.19	0.750
	Unspecified insurance	142	0.40	29.47	16.11	42.82	0.176
	No insurance or coverage	265	0.75	61.21	35.17	87.24	0.096

Table 3. Mean stigma score by clinical characteristics among diagnosed HIV-infected persons in Illinois, 2015-2017 MMP

		Weighted					p
		N	%	Mean	95% CI		value
Time since diagnosis	<1 year	407	1.14	39.92	29.57	50.27	Ref
	≥1 year	35,226	98.86	42.27	40.33	44.22	0.661
Currently taking ART	No	1,480	4.29	52.71	41.28	64.14	Ref
	Yes	33,053	95.71	41.81	39.82	43.81	0.066
Viral load in last 12 months	<200 copies/ml	22,654	63.57	41.29	38.89	43.69	Ref
	≥200 copies/ml or no data	12,980	36.43	43.93	40.69	47.17	0.200
Unmet need	Yes, ≥1 unmet need	18,938	53.56	48.61	45.89	51.33	Ref
	No	16,030	45.33	35.23	32.82	37.65	<.0001
	Didn't need any service	391	1.11	20.16	4.18	36.13	0.001
Depression*	No depression	28,442	80.72	39.20	37.15	41.26	Ref
	Major depression	3,639	10.33	59.29	53.50	65.07	<.0001
	Other depression	3,155	8.96	49.99	43.63	56.35	0.002
Anxiety	No anxiety	27,187	77.07	38.32	36.26	40.38	Ref
	Mild anxiety	2,051	5.81	49.91	42.32	57.50	0.004
	Moderate anxiety	3,061	8.68	50.69	43.86	57.52	0.001
	Severe anxiety	2,976	8.44	64.35	58.83	69.87	<.0001
Alcohol use in the past 30 days	Yes	14,836	42.08	43.26	40.12	46.41	Ref
	No	20,417	57.92	41.59	39.16	44.02	0.830
Injection or non-injection drug use in the past 12 months	Yes	22,395	63.83	41.64	39.17	44.10	Ref
	No	12,689	36.17	43.24	40.05	46.42	0.437

*Severity of depression based on Kroenke and Spitzer's (2002) algorithm

Further subgroup analysis was performed to examine stigma by race/ethnicity and gender, and by age group and viral suppression status. The results are listed in Table 4 and Table 5. As Table 4 shows, non-Hispanic Black and Hispanic females had much higher stigma score than non-Hispanic White females. Score was close to 40% higher in Hispanic/Latino females and 12% higher in non-Hispanic Black females. In Table 5, stigma score is listed by age group and by viral suppression status. Persons under the age of 45 years who were not virally suppressed had a higher stigma score compared to persons age 45 years and older.

Table 4. Stigma score by race/ethnicity and gender

	Male	Female
White, non-Hispanic	36.87	46.85
Black, non-Hispanic	39.60	52.23
Hispanic or Latino	44.50	64.90
Other	41.58	62.42

Table 5. Stigma score by age and viral suppression status

	Viral suppression	
	<200 copies/ml	≥200 copies/ml
18-24 yrs	40.86	46.41
25-34 yrs	41.67	46.93
35-44 yrs	40.23	45.73
45-54 yrs	40.67	41.28
≥55 yrs	42.58	41.41

Summary

This analysis shows that there is a high level of HIV-related stigma among HIV-infected adults in Illinois. More than two-thirds of study participants said it was difficult to tell others about their HIV infection, which could have implications for disclosing their HIV status to sex partners. This is consistent with previous literature that suggests HIV-related stigma is associated with low disclosure of HIV status [4,8].

Overall, females had higher stigma score than males. Compared to non-Hispanic Whites, non-Hispanic Blacks and Latinos had higher stigma score. Subgroup analysis by combined race/ethnicity and gender groups further showed that among women, Hispanic/Latina women reported the highest average stigma score, followed by non-Hispanic Black women, whereas non-Hispanic White women reported the lowest score. These racial/ethnic and gender differences in stigma burden may help inform stigma reduction efforts by identifying key groups in need of intervention [4]. Higher HIV-related stigma score was associated with several social determinants of health, including education, poverty, homelessness, and insurance type among HIV-infected adults. No association between HIV-related stigma and viral load suppression was found. These findings are consistent with recently published national data [4].

A strong association between HIV-related stigma and unmet needs was found in the present analysis, suggesting that stigma may be a barrier to access to care and to services among HIV-infected individuals. In addition, the present analysis found a strong correlation between HIV-related stigma and depression and anxiety. Combined, these factors may serve as barriers to accessing needed care and services.

HIV-infected individuals who were not on ART had higher stigma score (bordering significance). Considering that the majority (95%) of study participants were currently on ART, this result strongly suggests that stigma may be an important factor preventing people from seeking care or taking ART. Furthermore, even though there is a lack of strong evidence that stigma impacts viral suppression, subgroup analysis results indicate that among persons under the age of 45 who did not achieve viral suppression had higher stigma score. This result is consistent with previous studies that suggest tailored stigma-reduction interventions may be needed to address stigma among younger age groups [4].

The results of this analysis indicate an urgent need to develop effective interventions to reduce HIV/AIDS-related stigma in persons living with HIV/AIDS. Although the prevalence of stigma and its impacts on the lives of persons living with HIV/AIDS have been extensively studied, information on effective interventions to reduce stigma is limited. Multiple strategies, including awareness raising , health service provision, community mobilization, regulatory law, and support provision have been proposed, and the existing literature suggests multiple strategies that intervene at personal and environmental levels may be most effective [9]. It is therefore recommended that HIV/AIDS intervention planning group further examines the stigma issue in persons living with HIV/AIDS and adapt a comprehensive intervention strategy in terms of the population being targeted and the socio-structural and cultural context.

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