Prevalence of HIV-Related Stigma and the Association With HIV Treatment Engagement and Antiretroviral Therapy Adherence Among People With HIV

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**Presenting on behalf of the authors.*

Key Takeaways

- **A systematic literature review (SLR) evaluating HIV-related stigma examined data on prevalence and associations with treatment engagement and outcomes across the HIV care continuum**
- **HIV-related stigma was broadly reported among people with HIV and negatively impacted engagement and/or retention in HIV care and adherence to antiretroviral therapy (ART)**
- **These findings demonstrate an urgent need for prioritized interventions that reduce HIV-related stigma to improve both treatment outcomes and broader quality of life among people with HIV**

Introduction

- Here we summarize data on prevalence and associations between different forms of HIV-related stigma and treatment engagement and outcomes across the HIV care continuum as part of a SLR evaluating 6 research questions on HIV-related stigma

Methods

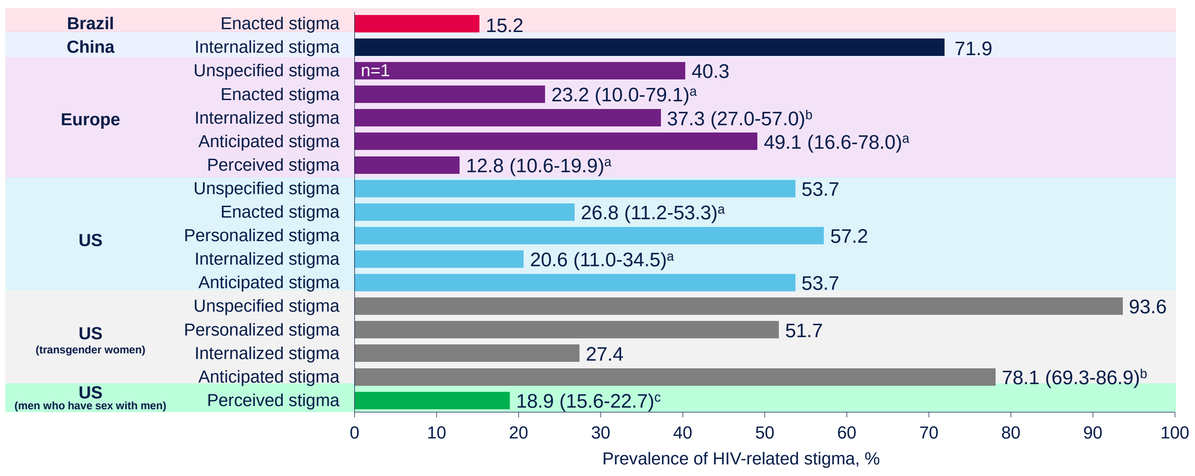
- Searches were conducted in MEDLINE® and Embase® via the OVID platform from database inception (care continuum search) or May 2020 (prevalence search) to May 2023
- Relevant conferences, SLR bibliographies, and websites from 2021 to 2023 were also searched
- Eligibility criteria were applied using the Condition, Context, and Population framework
- Inclusion criteria for both research questions included studies reporting HIV-related stigma, which encompassed social attitudes or perceptions toward HIV, fear of discrimination, and anxiety around sharing HIV status, among adolescents (aged 12-18 years) and adults (aged >18 years) with HIV
- PRISMA guidelines were followed
  - Records were independently screened by 2 reviewers until ≥90% inter-rater reliability was achieved
  - Data were extracted by a single reviewer and validated by a second

Results

Studies Identified

- The SLR identified 15 studies reporting prevalence of HIV-related stigma and 29 studies reporting associations between HIV-related stigma and treatment outcomes, including engagement/retention in HIV care and ART adherence

Figure 1. Summary of Prevalence of HIV-Related Stigma Forms Reported by Geographic Location (Interpretation Should Be Done With Caution and Comparisons Are Limited Due to Variations in Study Design, Populations, and Methodologies)



[a]Weighted average calculated from across included studies (range reported in parentheses). [b]Average calculated from different stigma statements within the same study (range reported in parentheses). [c]Average calculated from different time points in a single study (range reported in parentheses).

Prevalence of HIV-Related Stigma

- The reported prevalence of HIV-related stigma was broad across multiple forms of stigma and geographic locations (Figure 1)
  - Variability was partially due to methodological differences (eg, inconsistency in measuring prevalence, reported outcomes not standardized), which limits comparability and conclusions about true rates
- 2 studies reported an increase in HIV-related stigma over time
  - The prevalence of enacted stigma in healthcare settings in the Netherlands increased between 2007 (hospital: 26.2%; dentist: 28.8%; general practitioner: 19.2%) and 2019-2020 (hospital: 34.3%; dentist: 34.0%; general practitioner: 23.2%)[1]
  - The prevalence of perceived HIV-related stigma in men who have sex with men in San Francisco increased from 15.6% in 2014 to 22.7% in 2017[2]
- High levels of HIV-related stigma were reported in specific populations with HIV, including transgender people and men who have sex with men (n=2)

Table 1. Summary of Studies Assessing the Association of HIV-Related Stigma and Initiation of HIV Care or Engagement/Retention in Healthcare

Author, year, location	Study design	Form of HIV-related stigma	Outcome	Regression: Logistic (high vs low stigma) OR (95% CI)	*P* value
Unadjusted analysis					
Kerrigan 2017, Brazil[3]	Cross-sectional	Unspecified	Missed HIV care and treatment visits	1.43 (1.09, 1.89)	<0.05
Takada 2020, US[4]	Cross-sectional	Unspecified	Engagement with HIV care (≥1 HIV primary care visit) 12 months before entering jail	0.79 (0.53, 1.19)	>0.05
Pearson 2021, US[5]	Cross-sectional	Internalized	Attendance at next HIV primary care appointment after stigma assessment	0.89 (0.84, 0.95)	<0.0001
			Attendance at all HIV primary care appointments in next 12 months after stigma assessment	0.86 (0.82, 0.91)	
Reif 2019, US[6]	Cross-sectional	Internalized	Missed HIV care appointment in last 6 months	0.59 (0.14)[a]	<0.05
Petroll 2023, US[7]	Cross-sectional	Perceived[b]	Lower engagement with HIV care	1.05 (NR)	0.84
		Perceived[c]		1.59 (NR)	<0.001
Wiginton 2021, Europe[8]	Cross-sectional	Unspecified (overall)	Reported unmet needs in peer support	1.37 (1.30, 1.44)[d]	NR
			Reported unmet needs in access to chronic health conditions management	1.43 (1.35, 1.50)[d]	
			Reported unmet needs in access to psychological care	1.44 (1.37, 1.52)[d]	
			Reported unmet needs in access to isolation help	1.45 (1.38, 1.53)[d]	
Adjusted analysis					
Christopoulos 2019, US[9]	Cross-sectional	Internalized	Poor retention in HIV care (≥2 missed primary care visits in prior year)	1.12 (1.05, 1.20)[e]	0.001
			Lack of 6-month primary care visit consistency (as part of HIV care)	1.09 (1.02, 1.17)[e]	0.008
Hussen 2015, US[10]	Cross-sectional	Internalized	≥1 missed doctors' appointments in last 3 months (as part of HIV care)	0.95 (0.91, 0.99)	0.03
Molina 2018, US[11]	Cross-sectional	Enacted	Regular breast healthcare engagement (reporting clinical breast exam once in a year)	0.97 (0.93, 1.01)[f]	0.17
		Internalized		0.95 (0.91, 0.99)[f]	0.02
				Logistic (low vs high stigma)	
Yigit 2020, US[12]	Prospective	Internalized	HIV visit adherence in the 48-week study period	2.17 (1.09, 4.35)[g]	0.03
				Unstandardized linear (high vs low stigma)	
				β value (SE)	***P* value**
Rice 2017, US[13]	Cross-sectional	Internalized	Lower HIV visit adherence	−0.04 (0.02)	0.04
Petroll 2023, US[7]	Cross-sectional	Perceived[b]	Low engagement in HIV care	0.05 (0.24)	NR
		Perceived[c]		0.46 (0.10)	NR

CNICS, Center for AIDS Research (CFAR) Network of Integrated Clinical Systems; NR, not reported; OR, odds ratio. [a]Standard error. [b]33-item HIV stigma scale used to measure perceived stigma. [c]HIV barriers to care scale (perceived stigma against people with HIV in their community: 1 item) used to measure perceived stigma. [d]Unadjusted prevalence ratio (endorsing stigma vs not endorsing stigma). [e]Adjusted for age, gender identity, sexual orientation, race/ethnicity, length of time in CNICS, and site. [f]Adjusted for educational attainment and family history of breast cancer. [g]Adjusted for age, race, gender, insurance status, and site.

Effect of HIV-Related Stigma on Engagement/Retention in Healthcare and ART Adherence

- Increased levels of HIV-related stigma were significantly associated with reduced engagement/retention in general care (2/11 studies) and HIV-specific healthcare (8/11 studies; Table 1)
- Increased levels of HIV-related stigma were significantly associated with suboptimal ART adherence in 16/20 studies (Table 2)
- Included studies support the hypothesis that high levels of HIV-related stigma in healthcare settings can discourage people with HIV from engaging in HIV care and adhering to HIV treatment, potentially contributing to unsuppressed viral load

Table 2. Summary of Studies Assessing the Association of HIV-Related Stigma and HIV Treatment Adherence

Author, year, location	Study design	Form of HIV-related stigma	Outcome	Regression: Logistic (high vs low stigma) OR (95% CI)	*P* value
Unadjusted analysis					
Kerrigan 2017, Brazil[3]	Cross-sectional	Unspecified	ART adherence in last 4 days	0.60 (0.39, 0.92)	<0.05
Halkitis 2014, US[14]	Cross-sectional	Unspecified	Missing ART doses in past 4 days	1.05 (1.00, 1.10)	<0.05
			Taking ART doses outside specified schedule in past 4 days	1.04 (1.01, 1.08)	<0.05
			Failing to follow ART dosing instructions	1.08 (1.03, 1.13)	<0.01
Algarin 2020, US[15]	Retrospective	High enacted	ART non-adherence (<95%)	1.71 (1.08, 2.70)	0.02
		Moderate enacted		1.15 (0.82, 1.61)	0.43
		Healthcare-specific enacted		1.84 (1.15, 2.94)	0.01
Shrestha 2019, US[16]	Cross-sectional	Enacted	ART adherence (≥95%)	0.78 (0.51, 1.20)	0.27
		Internalized		0.77 (0.54, 1.09)	0.14
		Anticipated		0.62 (0.39, 0.98)	0.04
Meyers-Pantele 2022, US[17]	RCT	Personalized (enacted)	30-day ART adherence at 3-month follow-up	0.98 (0.96, 1.01)	>0.05
			30-day ART adherence at 6-month follow-up	0.97 (0.94, 0.99)	<0.01
Bogart 2015, US[18]	Cross-sectional	Perceived alter[a]	ART adherence	0.36 (0.17, 0.76)	<0.01
Rudolph 2022, US[19]	Cross-sectional	Internalized	ART adherence	0.64 (0.43, 0.95)[b]	NR
Adjusted analysis					
Seghatol-Eslami 2017, US[20]	Cross-sectional	Internalized	ART adherence	0.61 (0.34, 1.08)[c]	0.09
Turan 2016, US[21]	Cross-sectional	Internalized	ART adherence	0.76 (0.58, 0.99)[d]	0.042
				0.69 (0.52, 0.91)[d,e]	0.009
Blake Helms 2017, US[22]	Cross-sectional	Internalized	HIV medication adherence	0.54 (0.31, 0.92)[f]	0.02
Turan 2019, US[23]	Longitudinal	Internalized	ART adherence at ~2-year follow-up	0.61 (0.45, 0.82)[g]	0.001
Rice 2019, US[24]	Cross-sectional	Anticipated stigma in healthcare setting	ART adherence	0.64 (NR)[h]	0.004
		Enacted stigma in healthcare setting		0.58 (NR)[i]	0.01
Shrestha 2019, US[16]	Cross-sectional	Anticipated	ART adherence (≥95%)	0.38 (0.18, 0.83)	0.02
				Logistic (low vs high stigma)	
Yigit 2020, US[12]	Prospective	Internalized	ART adherence	2.05 (1.06, 3.98)[j]	0.03
				Linear (high vs low stigma)	
				β value (SE)	***P* value**
Unstandardized analysis					
Stutterheim 2022, Europe[1]	Cross-sectional	Perceived	ART adherence	−0.50 (1.15)	NS
Seghatol-Eslami 2017, US[20]	Cross-sectional	Internalized	ART adherence self-efficacy	−0.43 (NR)	0.005
Reif 2019, US[6]	Cross-sectional	Internalized	HIV medication adherence	5.61 (1.91) [bivariate coefficient]	<0.05
				4.90 (2.13) [multivariate coefficient]	<0.05
		Enacted		2.23 (−3.35, −1.12)[k] [multivariate coefficient]	<0.01
Rendina 2019, US[25]	Cross-sectional	Unspecified	ART adherence	−0.36 (−1.29, 0.63)[k]	>0.05
Standardized analysis					
Stutterheim 2022, Europe[1]	Cross-sectional	Perceived	ART adherence	−0.04	NS
Camacho 2020, US[26]	Cross-sectional	Anticipated	ART adherence	0.01 (−0.08, 0.08)[k]	0.91
Kalichman 2022, US[27]	Cross-sectional	Anticipated	ART adherence	−0.12 (NR)	0.074
		Enacted		−0.11 (NR)	0.08
Meyers-Pantele 2022, US[17]	RCT	Personalized (enacted)	7-day ART adherence at 3-month follow-up	−0.15 (−0.26, −0.03)[k]	<0.05
			7-day ART adherence at 6-month follow-up	0.02 (−0.10, 0.14)[k]	>0.05
Rendina 2019, US[25]	Cross-sectional	Unspecified	ART adherence	−0.08 (NR)	>0.05
Takada 2020, US[4]	Cross-sectional	Unspecified	ART adherence (30 days before incarceration)	−8.10 (−14.97, −1.23)[k]	<0.05
Mitzel 2015, US[28]	Cross-sectional	Unspecified	Self-reported HIV medication adherence in past week	−0.34 (NR)	<0.01

NR, not reported; NS, not significant; OR, odds ratio; RCT, randomized controlled trial; SES, socioeconomic status. [a]Perceived alter stigma described as a person within a participant's social network. [b]Relative risk (95% CI). [c]Adjusted by age, race, gender, SES, and ART duration. [d]Adjusted by race, age, ART duration, injection and non-injection drug use, income, and education. [e]Reported for a subpopulation of women who identified as racial or ethnic minorities in a US cohort of women with HIV. [f]Adjusted by age, racial identify, gender identity, SES, and ART duration. [g]Adjusted by ethno-racial identity, age, ART duration, illicit drug use, income, education, and US region (south vs other). [h]Adjusted by anticipated stigma from all other sources. [i]Adjusted by enacted stigma from all other sources. [j]Adjusted by age, race, gender, insurance status, and site. [k]Reported 95% CI.

Conclusions

- This SLR found that HIV-related stigma in people with HIV was broadly reported and negatively impacted engagement/retention in HIV care and adherence to ART
- Although interpretation of prevalence results is limited, studies identified that HIV-related stigma increased over time and was high in transgender people and men who have sex with men
- These findings reinforce the complexity of HIV-related stigma and its cascading effects on health outcomes
- These findings underscore the need for strategic interventions to reduce HIV-related stigma and enhance treatment outcomes for people with HIV
- Prioritization of strategies to decrease HIV-related stigma at every point of contact across the HIV care continuum is warranted

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