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Persisting HIV-Related Stigma Among an Outpatient US Clinic Population

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Abstract

Despite advancements in the public's understanding of HIV infection, stigma towards individuals living with HIV persists. Stigma has been associated with adverse health outcomes, including diminished engagement in care, poor medication adherence, and increased participation in HIV transmission risk behaviors. We evaluated the level of perceived stigma and its relationship to other psychosocial and medical factors among a sample of 201 individuals with HIV engaged in care. The Reece Stigma Scale was utilized to determine the level of felt stigma experienced by participants, with stigma scores ranging from 0 (no perceived stigma) to 45 (high perceived stigma). The overall mean stigma score was 21.7 (SD 8.7, range 9–45). In univariate analysis, stigma scores were higher among women, African Americans, younger participants, and individuals with less education. Higher stigma scores were also found among individuals who reported having fair to poor overall health, moderate to severe symptoms of depression and anxiety, and those with a current diagnosis of alcohol dependence, GAD, agoraphobia, pain disorder, and current smokers ($p < 0.05$ for all). After controlling for significant factors in univariate analyses, higher stigma scores were independently associated with individuals with anxiety symptoms ($p< 0.001$) and heterosexual individuals ($p < 0.05$). These analyses highlight that stigma persists among individuals with HIV and may play an important role in HIV care. The relationship between psychiatric disorders and psychosocial factors highlights an opportunity to develop interventions that will reduce both stigma and these common comorbidities.

Keywords

stigma; HIV/AIDS; psychiatric disorders; psychological distress; mental illness

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Introduction

Despite significant advances in HIV care, HIV-related stigma remains a problematic component of effective disease management.[1] Societal perceptions and biases about HIV infection persist, and result in stigma. This contributes to psychological distress and directly affects health outcomes and risk behaviors.[2–9] Community reaction to HIV infection has developed stigma primarily related to the behaviors associated with a higher risk of HIV acquisition and the characteristics of certain groups that have historically been most affected by the disease (e.g. men who have sex with men and injection drug users).[10] Stigma, both externalized and internalized, has been identified as a barrier to HIV testing and engagement into care; as such, addressing stigma is an integral component of HIV prevention efforts.[8] Although stigma is a contributing factor to psychological distress, it is unclear if and how it relates to psychiatric disorders, which often complicate HIV management.[11, 12]

Applied to a number of health and social issues, stigma is often difficult to quantify. Early descriptions of stigma emphasized its relation to the deviation of individuals from social norms, resulting in cognitive affirmations of unworthiness.[13–16] The modern definition of stigma expands on this interpretation to include enacted stigma, or outward expressions of discrimination and rejection from community members, and felt stigma, or the perception of others' discrediting thoughts, feelings, and behaviors.[8, 9] Broadly, HIV-related stigma includes feelings of social isolation and rejection, and has an adverse impact on engagement in medical care and self-care behaviors in certain cultural contexts.[8, 9, 17, 18] Amplifying feelings of social anxiety, these perceptions also negatively influence serostatus disclosure patterns while increasing engagement in HIV transmission risk behaviors.[19]

Defining HIV-related stigma is challenging given that diverse communities express and experience it differently. As HIV infection has transitioned from a uniformly fatal illness to a manageable chronic disease among individuals who have access and adhere to medical care, fewer studies of stigma have been conducted in the U.S. compared to earlier years of the epidemic.[20] Recent studies have been conducted in developing regions of the world and have identified lack of knowledge and the fear associated with HIV infection as two factors contributing to increased HIV-related stigma on the community level,[19, 21] yet over time developing regions are likely to need to focus their work on reducing stigma and HIV-related discrimination as well.[22] Unfortunately, in the U.S., the advancement of HIV medical care may cause providers and researchers to assume that stigma has effectively diminished.

This study was conducted to examine HIV-related stigma as experienced by a cohort of individuals with HIV engaged in medical care at a Midwestern U.S. outpatient clinic. Using a measure that focuses on individual perceptions of experienced stigma,[15,16] the current study aimed to identify the prevalence of stigma among this population and its association with psychiatric disorders and HIV-related health outcomes in the era of combination antiretroviral therapy (cART).

Methods

Individuals with HIV, 18 years of age or older, presenting for care at the Washington University HIV Clinic were eligible to participate in a 2 hour interview. Of those who enrolled in the study, 72% completed the interview. Individuals were remunerated for participation in the study and received transportation vouchers, when necessary. The computerized interview was conducted by trained interviewers in a private room, and all study materials were approved by the Washington University Human Protection Office. All participants provided written informed consent before participation.

HIV-related stigma was measured using the Reece Stigma Scale, a 9-item instrument with possible scores ranging from 0 (no perceived stigma) to 45 (high perceived stigma). The scale has been applied previously in a southeastern U.S. urban clinic setting, as well as in sub-Saharan Africa.[23–25] Widely accepted for conducting diagnostic interviews both in practice and for research purposes, the Diagnostic Interview Schedule (DIS) was utilized to determine current psychiatric diagnoses (within the past 12 months) through structured computerized interviews with trained "lay persons."[26] These diagnostic interviews identified current (within 12 months) psychiatric disorders. Additional results of these interviews are described elsewhere. Symptoms of depression and severity were assessed using the Patient Health Questionnaire-9[27] and quality of life was measured with the Short-Form 12, as has been used previously in populations with HIV.[28] Sexual orientation was calculated by self-reports of sex partner gender among those sexually active with in the previous 4 months.

Data were abstracted from participants' medical records to ascertain the most recent CD4 cell count, and HIV viral load, and length of time since HIV diagnosis (in years). CART was defined as the use of ≥ 3 antiretroviral drugs from 2 or more classes.

Variables were dichotomized as follows: HIV viral loads (< 400 copies/mL and ≥ 400 copies/mL); education level (≤ high school graduate or equivalent or > high school degree);employment status (unemployed, including those receiving disability benefits, and employed, part- or full-time);annual income (≤ $10,000 and > $10,000); and depression severity (those who expressed symptoms of major or other depressive disorders (MDD/ODD) within the past 2 weeks and those who did not).

Statistical Analyses

Descriptive analyses were utilized to assess the sample. A principal component analysis was conducted using a varimax rotation to assess a one factor solution for the Reece Stigma Scale, which resulted in 50.5% of the variablility to be explained by one factor. Univariate analyses were conducted to assess relationships between sociodemographic and psychological characteristics and mean stigma scores. Linear regression models were created to evaluate independent relationships between stigma scores and sociodemographic and psychiatric determinants using a backward stepwise approach. These models included variables which were associated with higher stigma scores in univariate analyses ($p < 0.10$). All tests were 2-tailed with $p < 0.05$ considered to be significant. Data analyses were performed using SPSS software (version 19.0, Chicago, IL).

Results

A sample of 201 individuals with HIV infection completed the interviews; 69% male, 72% African American, 63% unemployed, with a mean age of 43 years. Overall, 83% of individuals were receiving cART and 78% achieved virologic suppression (< 400 copies/mL) on the most recent evaluation. The most prevalent current psychiatric disorders, as determined using the DIS, were Pain Disorder (42%), Major Depressive Episode (38%), Generalized Anxiety Disorder (14%), and Alcohol Dependence (17%). Additional demographic characteristics are included in Table 1.

The overall mean felt stigma score was 21.7 (SD = 8.7; range 9–45). Among the nine items comprising the Reece Stigma Scale, the most prominently endorsed symptoms were that individuals1) felt it was important to keep their HIV status secret, ii) that they felt most people did not want to date someone with HIV and as a result avoided dating, and iii) they were worried about disclosure of their HIV status and avoided situations where this could occur. Table 2 includes a summary of each item and the frequency of responses, as well as the results of the principal component analysis.

In univariate analyses, elevated felt stigma scores were more prevalent among women, those with less education, and African Americans ($p < 0.05$ for all). Individuals who reported having poor to fair overall health had higher stigma scores than those reporting excellent to good health, as well as current smokers ($p < 0.05$ for both). Higher stigma scores were associated with reporting moderate-severe symptoms of depression and anxiety, being diagnosed with current generalized anxiety disorder (GAD), agoraphobia, alcohol dependence, and pain disorder ($p < 0.05$ for all). We identified no significant differences in stigma scores by HIV viral load, CD4 cell count, or health risk behaviors (including multiple current sexual partners, unprotected sex at last sexual encounter, and current alcohol or illicit drug use).

In linear regression analyses, we controlled for significant associations, individuals who were heterosexual and had moderate to severe anxiety symptoms ($p < 0.05$ for both) were more likely to express higher stigma scores. These results are detailed in Table 3.

Discussion

Stigma remains an important aspect of HIV disease management, even among individuals engaged in medical care. Felt stigma was independently associated with individuals who were heterosexual and those endorsing moderate to severe anxiety symptoms. We identified patterns of increased felt stigma reported among those with less education, African Americans, individuals who rated poorer general health, and current smokers. Additionally, individuals who also endorse moderate to severe symptoms of depression and anxiety; as well as a current diagnosis of GAD, agoraphobia, alcohol dependence and pain disorder. These findings suggest that felt stigma not only persists among populations with HIV in the U.S., but also has a complex relationship with social and behavioral factors as well as psychiatric comorbidities.

Independently, our study identified that heterosexual individuals were more likely to express felt HIV-related stigma. This difference has important implications. Historically, stigma was highest among communities of men who have sex with men or gay men. We hypothesize that the MSM population has a more established, more readily available support network due being the community with longest impacted; while heterosexual populations are more socially isolated due to the limited established support network within their community. We measured sexual orientation among individuals who had reported having sex within the past 4 months, which provided a more accurate sexual history. Yet, it did not allow our stigma analyses to capture those who were not sexually active by their orientation. However, this finding highlights higher stigma may be increasing transmission risk, since higher felt stigma has been associated with less serostatus disclosure and condom use.[29, 30] Additionally, we identified that endorsing moderate to severe anxiety symptoms significantly increased the risk of felt stigma. These findings are important to highlight and suggest that anxiety symptoms are in some ways, easier to intervene on rather than a diagnosed psychiatric disorder as they tend to fluctuate more often and are potentially manageable with simple behavioral interventions.

The univariate analyses identified patterns of higher felt stigma among individuals who were less educated, African American, expressing poorer general health, and those who were current smokers. HIV is a disease that disproportionately affects low income populations;[1] some of the complexities related to this disparity include poorer overall quality of life indicators, less education attainment, and relative to HIV, more discrimination of individuals with HIV.[30, 31] We need to understand the driving forces of how stigma is operationalized in communities to highlight HIV transmission risk behaviors that may be fueling the epidemic.[17, 23, 32]

Populations with HIV have higher smoking rates than uninfected populations and they may be using smoking as a coping strategy.[33, 34] Managing HIV is complex; thus identifying healthy coping strategies in order to address chronic disease risk behaviors will enhance health outcomes as individuals with HIV age. Additionally, lower perceived general overall health was associated with higher rates of stigma, similar to previous findings that identified an association between poor perceived health and more severe depressive symptoms to poorer medication adherence among individuals engaged in HIV care.[2] Addressing the perception of wellness, being able to manage HIV infection effectively may empower individuals and reduce stigma, demonstrating the interrelatedness of wellness and adherence to care and medications.

We found HIV-related stigma to co-occur with more severe symptoms of depression and anxiety. These relationships help describe what are the underlying psychiatric processes related to felt stigma. More purposeful screening and treatment of depression and anxiety are necessary components of HIV care. Additionally, higher rates of felt stigma were more common among individuals with current alcohol dependence. This finding suggests another maladaptive coping strategy, as individuals may self-medicate with alcohol and other substances. While we cannot be certain about causation, the association of stigma to affective mood disorders and substance abuse disorders highlights a barrier to successful long term management of HIV disease that needs to be addressed in clinic- and community-

based interventions. Identifying patterns of psychological and substance abuse disorders and perceived stigma may help health care providers identify patient needs and offer more appropriate support to assist with disease management.

This study aimed to identify relationships between stigma, psychiatric disorders and psychological distress, and HIV-related health outcomes in order to clarify how stigma may be defined among individuals with HIV in the era of cART in the U.S. Current trends in intervention development stress the importance of addressing stigma among populations with HIV. Given the variability in cultural and community norms, interventions will likely require tailoring for populations of interest. Specifically, identifying patterns of psychological distress or psychiatric disorders that are often related to higher stigma will be beneficial for providers to guide needed interventions.

Developing and focusing interventions on newly infected or those not engaged in care may be beneficial to addressing stigma. Opt-out HIV testing has been shown to have a positive impact on HIV-related stigma due to the lack of risk-based testing.[35, 36] The linkage to care systems that are increasingly available throughout the U.S. may serve as an opportunity to deliver messages that help alleviate HIV-related stigma, as well as providing appropriate referrals. Additionally, integrating peer navigators will be even further beneficial as they speak from experience and have matured through the stigma experience.

Nevertheless, findings from the current study create opportunities for advancing interventions focused on HIV-related stigma. Although social change can be difficult to create, some communities have successfully utilized mass media strategies to address HIV-related stigma by increasing HIV testing and condom use.[37] The Centers for Disease Control and Prevention has sponsored several campaigns focused on increasing HIV testing; however, these interventions may have minimal exposure beyond communities of high HIV prevalence, where stigma is more likely to exist. Furthermore, health communication strategies may be limited due to cost and sustainability.

While we were unable to detect significant associations between stigma scores, engagement in risk behaviors, and HIV outcomes, selection bias may have contributed to these results. Given that our sample was actively engaged in HIV care at the time of recruitment, we recognize a selection bias as we were not able to fully explore the impact of stigma on HIV-related health outcomes. Since this was a cross-sectional study, we are unable to identify directionality of the stigma and anxiety symptoms; longitudinal studies may be able to better clarify the relationship between these symptoms. Further, we defined sexual orientation only among individuals who endorsed being sexually active within the previous 4 months. Additionally, our sample size was limited by the depth of the interviews. While the psychiatric diagnoses identified through the interviews were based on valid and reliable measures, these reports do no substitute for clinical diagnoses. Despite these limitations, this study revealed that measurable levels of felt stigma persist among specific HIV-positive communities and are associated with psychiatric comorbidities, as well as ., while also providing insight about the definition of stigma within populations with HIV today.

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Table 1

Sample Characteristics (n = 201)

Race	**n**	**%**
African American/ Other minorities	146	72.3
Caucasian	55	27.2
Gender		
Male	138	68.8
Female	61	30.2
Mean Age	43.06 (SD 11.05)	
Annual Income (n = 199)		
< $10,000	102	50.5
≥ $10,000	97	48
Employment Status		
Unemployed	126	62.9
Employed (part- or full- time)	75	37.1
Education completed		
≤High School/equivalent	98	48.8
> High School	103	51.0
Consider self homeless	20	9.9
Receiving anti-depressant	64	31.8
Receiving cART	167	82.7
HIV viral load		
< 400 copies/mL	141	70.1
≥ 400 copies/mL	60	29.8
CD4 cell count (n = 198)		
<200 cells/mm^3	44	22.2
200–499 cells/mm^3	68	34.3
>500 cells/mm^3	88	44.4
Sexual orientation (n =105)		
MSM	50	24.7
Heterosexual	50	24.7
Bisexual	5	2.5*
Overall health status		
Excellent	26	12.9
Very good	51	25.2
Good	67	33.2
Fair	45	22.3
Poor	12	5.9
Condom use at last sex	62	30.7
More than 1 sex partner in last 3 months	12	11.4
Mean number of alcoholic drinks in week (n = 136)	8.7	SD: 11.1
Number of participants using illicit drugs within past 30 days (n = 162)		

Race	**n**	**%**
Cocaine/crack	5	2.5
Marijuana (n = 162)	4	2.0
Inhalants (n =164)	5	2.5
PHQ-9 Depressive Symptoms (n = 166)		
No-Mild Depressive Symptoms (PHQ-9 <15)	141	84.9
Moderate- Severe Depressive Symptoms (PHQ-9 ≥15)	25	15.1
GAD-7 Anxiety Symptoms (n = 164)		
No-Mild GAD Symptoms (GAD-7 <10)	127	77.4
Moderate-Severe GAD Symptoms (GAD-7 ≥10)	127	22.6
Current Smokers	105	52.8
Non-Smokers	94	47.2
Stigma score by interquartiles		
0–14	53	26.2
15–21	53	26.2
22–28	52	25.7
29–45	44	21.8

cART = combination Antiretroviral Therapy; MSM= men who have sex with men

* not included in analyses due to small sample size

Table 2

Reece Stigma Scale of Item Endorsement by Sample

Item	Number (proportion) reporting sometimes, often, or always	Principal Component Analysis Eigenvalue
Felt having HIV was a punishment for things I had done in the past	65 (32.2%)	0.345
Felt that people were avoiding me because of my HIV status	48 (23.8%)	0.799
Feared that I would lose my friends if they learned about my HIV status	85 (42.3%)	0.657
Felt like people that I know were treating me differently because of my HIV status	63 (31.3%)	0.800
Felt like people looked down on me because I have HIV	64 (31.8%)	0.698
Avoided dating because most people don’t want a relationship with someone with HIV	115 (58.0%)	0.453
Avoided a situation because I was worried about people knowing I have HIV	109 (54.0%)	0.653
Was embarrassed about having HIV	102 (50.5%)	0.679
Felt that keeping my HIV status secret was important	157 (77.8%)	0.557

Table 3

Sociodemographic and HIV Management Associations with HIV-Related Stigma

	Univariate Associations with Stigma Mean (SD)	p value	Standardized Coefficients Beta	p value
Gender				
Male	20.93 (8.49)	0.09		
Female	23.21 (9.25)			
Age category				
18–25 years	25.43 (9.49)	0.172		
26–44 years	21.94 (8.67)			
≥45 years	20.84 (8.63)			
Education level (n = 168)				
≤ High School Diploma	23.19 (8.82)	0.012		
> High School Diploma	20.13 (8.41)			
Race				
African American/Other Minority	22.72 (8.76)	0.004		
Caucasian	18.76 (8.09)			
Sexual Orientation (n = 100)				
MSM	20.04 (8.20)	0.071	Ref	0.025
MSW/WSM	23.24 (9.27)		0.357	
Years with HIV (n = 194)				
0–5 years	22.31 (8.86)	0.201		
6–10 years	23.39 (9.46)			
>10 years	20.68 (8.32)			
Overall Health Status				
Excellent-good	20.41 (8.34)	0.001		
Fair-poor	25.09 (8.81)			
Current cART prescription (n = 165)	21.82 (8.77)	0.603		
HIV Viral Load > 400 copies/mL	21.80 (8.50)	0.874		
CD4 cell count, cells/mm3		0.845		
<200	22.05 (8.94)			
200–499	21.93 (8.48)			
>500	21.24 (9.01)			
Current Smokers	23.02 (8.75)	0.022		
Non-Smokers	20.18 (8.55)			
Distress Symptoms				
PHQ-9 Depressive Symptoms				
No-Mild Depressive Symptoms (PHQ-9 <15)	20.51 (8.49)	Ref		
Moderate- Severe Depressive Symptoms (PHQ-9 ≥15)	26.28 (8.82)	0.002		
GAD-7 Anxiety Symptoms				

	Univariate Associations with Stigma Mean (SD)	p value	Standardized Coefficients Beta	p value
No-Mild GAD Symptoms (GAD-7 <10)	19.90 (8.30)	Ref	Ref	
Moderate-Severe GAD Symptoms (GAD-7 ≥10)	26.65 (8.47)	0.001	0.367	0.001
Current DIS Diagnoses (within 12 months)				
Generalized Anxiety Disorder	24.44 (8.90)	0.07		
No GAD Diagnosis	21.26 (8.67)	Ref		
Agoraphobia	26.44 (8.02)	0.001		
No Agoraphobia Diagnosis	20.81 (8.61)	Ref		
Major Depressive Episode	22.00 (8.29)	0.712		
No Major Depressive Episode Diagnosis	21.53 (8.88)	Ref		
Alcohol Dependence	24.79 (8.12)	0.03		
No Alcohol Dependence Diagnosis	21.17 (8.86)	Ref		
Cocaine Dependence	22.92 (8.48)	0.476		
No Cocaine Dependence Diagnosis	21.55 (8.82)	Ref		
PTSD Disorder	24.70 (8.84)	0.089		
No PTSD Diagnosis	21.36 (8.78)	Ref		
Pain Disorder	23.96 (8.84)	0.002		
No Pain Disorder Diagnosis	20.04 (8.33)	Ref		

PHQ9 = Patient Health Questionnaire-9; GAD= Generalized Anxiety Disorder; DIS= Diagnostic Interview Schedule; MSM= men who have sex with men; MSW= men who have sex with women; WSM= women who have sex with men