#### **ORIGINAL PAPER**



# The Relationship of HIV-related Stigma and Health Care Outcomes in the US Deep South

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#### Abstract

HIV-related stigma is prevalent in the US Deep South; however, information regarding the types of stigma and their effects on HIV-related outcomes is limited. This study examined the prevalence of different forms of stigma and the association of stigma with medication and medical visit adherence in the Deep South. Survey participants included 201 individuals living with HIV recruited from Infectious Diseases Clinics (ID) and AIDS Service Organizations (ASOs) in four Deep South states. Study participants reported high levels of experienced, perceived, and internalized stigma. Multivariable analysis revealed that internalized stigma and recent stigmatizing experiences were significantly associated with poorer HIV medication adherence. Internalized stigma was also associated with having missed an HIV medical care visit in the last 6 months. These findings suggest the need to identify and develop effective interventions to address internalized HIV-related stigma and to address community HIV stigma to improve outcomes for individuals living with HIV.

Keywords HIV · Southern US · HIV-related stigma · Medication adherence

# Introduction

The US South, particularly the Deep South region, has been disproportionately affected by HIV. The Deep South<sup>1</sup> had the highest HIV diagnosis rates and HIV death rates of any region from 2008 to 2015 [1, 2]. A number of factors have been implicated as contributing to the disproportionate impact of HIV in the region including poorer overall health, higher sexually transmitted infection rates, lack of access to health care, and high levels of poverty [1–3]. [4, 5]. High levels of HIV-related stigma and discrimination have also been identified in the Deep South [6–8] and have been found to contribute to poorer health outcomes such as lower levels of medication adherence [9]. However, the evidence linking stigma to medication adherence in the Deep South is limited

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and few studies have examined the role of different types of stigma in influencing HIV-related outcomes [10, 11].

Stigma can exist in several different forms including experienced/enacted stigma, which is the occurrence of a specific act of discrimination, such as a breach of confidentiality or an insult to an individual living with HIV about the disease. Perceived community stigma is an individual's thoughts and observations of community-level stigma toward individuals living with HIV [12], and internalized stigma has been defined as "the degree to which people living with HIV endorse the negative beliefs and feelings associated with HIV/AIDS about themselves." [13] Another form of stigma, anticipated stigma, refers to fear of negative outcomes occurring if one's HIV status is disclosed or the expected consequences if an individual tests positive for HIV [12, 13]. The various types of stigma may affect health outcomes differently, thus it is important to examine their individual effects. For example, Earnshaw et al. examined the effects of different aspects of stigma among men living with HIV in the Bronx, NY and found internalized stigma to be associated with mental health measures and antiretroviral adherence while anticipated and enacted stigma were associated with physical well-being measures [14].

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HIV-related stigma is hypothesized to affect HIV-related health behaviors such as medication adherence directly as well as indirectly through an influence on factors such as mental health and substance use, which have been consistently associated with poorer adherence [15–18]. Several studies have identified that mental health acted as a mediator in the relationship between HIV-related stigma and HIV medication adherence [18–20], as greater internalized stigma predicted higher levels of psychiatric symptoms, which in turn was associated with poorer medication adherence. For example, a study by Sayles et al. conducted among individuals living with HIV in California determined that internalized stigma had an indirect effect on medication adherence through its influence on psychiatric symptoms. However, this study along with additional studies that examined behavioral health mediators of the relationship between HIV-related stigma and medication adherence were primarily conducted in large metropolitan areas outside the South, so may not be representative of the experiences of individuals living with HIV in the Deep South, with its unique cultural and religious landscape.

Despite the recent rise of other religious traditions, evangelical Protestantism has largely dominated the culture of this region [21]. The Deep South states are part of the Bible Belt, "...a region associated with fundamentalist Protestantism, puritanical mores and populated by adherents to denominations which believe in a literal interpretation of the Bible." [22] The Deep South as a region has a high percentage of people who say that homosexuality should be discouraged [23]. Focus group participants in an HIV Stigma Study conducted by the authors described high levels of LGBTrelated stigma present in churches in the region [24]. The Deep South also suffers from a history of institutionalized racism and a legacy of slavery that has broad implications for low black wealth accumulation, high black poverty rates, and increased racial bias [25–27].

The study described herein examined the relationship of internalized stigma with medication adherence and missed medical appointments among individuals living with HIV in the US Deep South. Although the primary focus of the study was the relationships of internalized stigma and health care outcomes, we also measured multiple types of stigma among individuals living with HIV in the Deep South, including experienced stigma, anticipated stigma, and perceived community stigma, and examined their relationships with health care outcomes. In addition, this study examined whether depressive symptoms mediated the relationship of internalized stigma with HIV medical appointment and medication adherence.

This study utilizes an adapted form of the theoretical framework of stigma conceptualized by Earnshaw and Chaudoir, the HIV stigma framework [13]. This framework postulates that internalized stigma is associated with mental

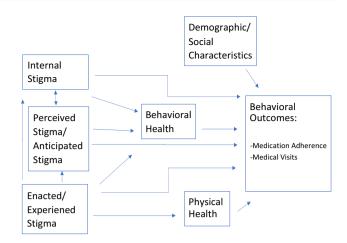


Fig. 1 Adapted HIV stigma framework

health concerns and health outcomes including antiretroviral adherence and medical care visits. Anticipated stigma and experienced stigma are also postulated to influence behavioral health as well as directly influencing physical health outcomes, such as CD4 count. The different forms of HIV-related stigma are hypothesized to be interconnected. Earnshaw et al. found evidence to support the HIV Stigma Framework model in a study of individuals living with HIV in the Bronx, New York [14]. Turan et al. further adapted the HIV Stigma Framework, including the addition of perceived stigma to the model, and conducted a study that identified the interconnected nature of the stigma types [10]. One such finding was that perceived community stigma leads to internalized stigma, which leads to anticipated community stigma, which in turn leads to lower medication adherence. For the purpose of this study, the adapted HIV Stigma Framework has been revised to include additional factors that relate to adherence to medical visits and medications (see Fig. 1).

## Methods

## **Participants and Procedures**

Surveys that included questions about HIV-related stigma and health outcomes were completed by 201 individuals living with HIV in 4 Deep South states: Alabama, Mississippi, South Carolina, and North Carolina between April 2016 and January 2017. Individuals were recruited to participate in the study primarily through Infectious Diseases (ID) Clinics (64%) in these states. The remaining participants were recruited through partnerships with AIDS Service Organizations (ASOs). Study staff were present at the ID clinics to ask all individuals living with HIV attending appointments that day if they were interested in completing an HIV stigma survey. At the ASOs, study staff were present for HIV support groups, at an HIV housing program, and at a substance use treatment program for individuals living with HIV to identify individuals interested in participating in the survey. Less than 10% of individuals approached regarding participation declined to complete the survey. Participants were provided with \$5 as compensation for completing the survey.

#### Measures

The participant survey included questions from standardized stigma scales including the Berger HIV Stigma Scale [28]. The Berger HIV Stigma Scale has adequate validity and reliability and contains four dimensions. These dimensions are negative self-image related stigma (measures internalized stigma), concern about public attitudes related to HIV, concern about HIV status disclosure and the anticipated consequences if HIV is disclosed, and personalized stigma, which is what someone has experienced when others know of their HIV status, such as "I lost friends by telling them I have HIV." [29] Response categories are "strongly agree," "agree," "disagree," and "strongly disagree." A total stigma scale score was calculated using all 40 of the HIV Stigma Scale items and subscale scores were calculated for each of the four HIV Stigma Scale subscales.

Items regarding stigma experiences from the verbal abuse subscale of the HIV/AIDS Stigma Instrument (HASI-P) by Holzemer et al. were also included in the survey to gather information about recent stigmatizing experiences to supplement the stigma perception information obtained through the HIV Stigma Scale [30]. The HASI-P verbal abuse subscale includes eight questions measuring experiences of verbal abuse related to HIV in the last 3 months such as "I was blamed for my HIV status." Response categories include "never," "once or twice," several times," and "most of the time." Individuals who had experienced an item at least once or twice in the last 3 months were scored as a 1 for the item and the items were added to provide a HASI-P verbal abuse subscale score. Cronbach's Alpha scale reliability coefficients were calculated for the HIV Stigma Scale and the HASI-P verbal abuse subscales for the study sample and found to be in the acceptable range at .966 and .935 respectively [31].

Self-reported medication adherence was assessed using a visual analog scale [32]. On this scale, participants selfreported the percentage of HIV medications that they regularly take as directed, ranging from 0 to 100%. Missed HIV medical appointments were measured with the question "In the past 6 months, how many times have you missed a scheduled appointment for HIV medical care?" The survey also contained demographic measures, questions regarding social support from the MOS social support scale, and information about depressive symptoms, which was measured with the PHQ-9 depression scale [33, 34]. A standard PHQ-9 cutoff of 10 was used to indicate probable moderate depression [34]. We measured substance use with a validated question regarding participant drug use [35].

#### **Statistical Analysis**

Descriptive statistics were used to examine participant characteristics and stigma experiences. Bivariable statistics, including t-tests and linear regression, were used to examine the relationship of HIV-related stigma with health care outcomes including having missed a medical appointment in the last 6 months and adherence to HIV medications. Multivariable analyses were performed using logistic regression to examine the relationship of the HIV Stigma Scale subscales with any self-reported missed appointments for HIV medical care in the last 6 months and using linear regression to examine the relationship of the HIV Stigma Scale subscales with self-reported percent adherent to antiretroviral medication. A separate regression equation was estimated for each stigma subscale due to the high correlation between the stigma types. Covariates were based on the theoretical framework and included demographics, depression, substance use, and social support.

For the HIV Stigma Scale, the PHQ-9, and the MOS social support scale, values were calculated as the average of the answered items as long as at least 75% of that scale's items were answered; otherwise the score was set to missing. For the HIV Stigma Scale, 34% of study participants were missing at least one of the 40 items; however, only 8% were missing more than 25% of the HIV Stigma Scale items. For the PHQ-9 and social support scale, 14% and 18% respectively were missing more than 25% of data on the scales. For the multivariable regression analyses regarding medication adherence and missed medical visits, the total percent missing data in the models were 16% and 18% respectively.

To examine the evidence that mental health mediates the relationship between stigma and the outcomes of interest, the mediation analysis method described by MacKinnon was utilized [36, 37]. This method includes the following steps: (step 1) fit a model with only the independent and dependent variables; (step 2) estimate the relationship between the independent variable and the mediating variable; (step 3) fit a model with the independent, mediating, and dependent variables in the model. Evidence consistent with a mediating relationship includes: (1) a significant relationship of the independent variable (stigma) to the dependent variable in step 1 (total effect); (2) a significant relationship of the independent variable (stigma) to the hypothesized mediating variable (depression); (3) a significant relationship of the mediating variable with the dependent variable when both the independent variable and mediating variable are

**Table 1** Participant characteristics (N = 201)

Characteristic	Number (%)
Female	107 (53.2)
Male	90 (44.8)
Transgender	4 (2.0)
African American	163 (81.1)
Caucasian	31 (15.4)
Other race	7 (3.5)
Hispanic/Latino	13 (6.5)
Black MSM	49 (24.4)
18–24	19 (9.6)
25–34	28 (14.1)
35–45	48 (24.3)
45 and over	103 (52.0)
Heterosexual	117 (59.1)
Gay/Lesbian/Bisexual	81 (40.9)
Disabled	6 (33.2)
Employed	68 (34.8)
Less than high school education	38 (19.0)
Completed high school	100 (50)
Any college	62 (31)
Alabama	37(18.4)
Mississippi	32 (15.0)
North Carolina	62 (30.9)
South Carolina	70 (34.8)
PHQ-9 score indicates major depression	52 (26.7)
Illicit substance use in the past year	68 (34.5)
Missed medical appointment in past 6 months	48 (25.8)
Adherence $\geq 95\%$	127 (65.1)
HIV Stigma Scale—total score (scale 1–4—higher score indicates less stigma)	2.67 (.66)
HIV Stigma Scale—internalized stigma subscale	2.91 (.72)
HIV Stigma Scale—personalized stigma subscale	2.79 (.77)
HIV Stigma Scale—disclosure stigma subscale	2.31 (.71)
HIV Stigma Scale—public attitudes stigma subscale	2.61 (.76)

included in the same model; and (4) the coefficient relating the independent variable to the dependent variable is closer to the null in step 3 (direct effect) than in step 1 (total effect).

## Results

A majority of survey participants were African American (81%) and 53% were female (Table 1). Forty-one percent dentified as gay, lesbian, or bisexual. One-third of participants reported being disabled and 18% had less than a high school education. Ten percent of participants were aged 18–24 and 76% were aged 35 and older. Nearly one-quarter of participants (27%) had a PHQ-9 score that qualified them as having a probable diagnosis of depression and 35% had Table 2 Experienced stigma in the last 3 months (Holzemer Scale)

Characteristic	Percentage that experienced item at least once or twice in the last 3 months
Someone insulted me	24.5
Blamed for HIV status	23.1
Told I had no future	21.8
Told God punishing me	23.5
Someone scolded me	24.5
I was called bad names	27.5
Someone mocked me when I passed by	22.5
Sang offensive songs	14.5

used illicit substances in the previous year. Twenty-six percent of respondents reported having missed an HIV medical appointment in the last six months and the average percent adherent to HIV medication was 89.3.

Thirty-six percent of participants reported experiencing at least one of the verbal abuse experiences on the Holzemer Scale (HASI-P) in the last 3 months. For example, onequarter reported being "insulted" because of their HIV status in the last three months. (Table 2). Twenty-four percent reported 3 or more different types of verbal abuse subscale experiences in the last 3 months.

Internalized stigma was reported by a substantial minority of participants. For example, 36% of participants agreed or strongly agreed with the statement "I feel guilty because I have HIV" (Table 3) and 28% agreed/strongly agreed that they "feel unclean because of HIV." In addition, relationships were report to be affected by HIV stigma, as nearly half (48%) reported that "it is easier to avoid friendships than worry about telling that I have HIV" and one-third reported that "since learning I have HIV, I feel set apart and isolated from the world."

#### Bivariable Analysis (Tables 4, 5)

## Stigma and Health Care Outcomes

Higher levels of internalized stigma (as measured by the HIV Stigma Scale internalized stigma subscale) were significantly associated with having missed any HIV medical appointments in the last 6 months. However, anticipated stigma related to disclosure, perceived community stigma, and stigma experiences, including the HIV personalized stigma scale subscale of the HIV Stigma Scale and the HASI-P verbal abuse experiences scale, were not associated with missed HIV medical appointments.

Internalized stigma was statistically significantly associated with poorer HIV medication adherence. In addition, the personalized stigma subscale was significantly

Statement	Strongly agree	Agree	Disagree	Strongly disagree
I feel I'm not as good a person as others because I have HIV	8.5	12.2	33.3	46.0
Having HIV makes me feel unclean	9.3	19.1	29.9	41.8
Having HIV in my body is disgusting to me	11.3	17.0	27.3	44.3
People's attitudes about HIV make me feel worse about myself	14.1	19.3	27.1	39.6
I feel guilty because I have HIV	11.9	23.9	26.9	37.8
I never feel ashamed of having HIV	21.3	22.3	29.3	27.1
It is easier to avoid friendships than worry about telling that I have HIV	19.3	28.9	27.3	24.6
Having HIV makes me feel that I'm a bad person	9.9	10.9	33.9	45.3
Since learning I have HIV, I feel set apart and isolated from the world	13.0	20.1	27.1	39.1
I work hard to keep my HIV a secret	20.9	21.4	32.6	25.1
As a rule, telling others that I have HIV has been a mistake	11.2	21.8	37.4	29.6
People who know I have HIV tend to ignore my good points	8.2	17.0	41.8	33.0
People seem afraid of me once they learn I have HIV	12.0	16.3	42.9	28.8

#### Table 3 HIV Stigma Scale-internalized stigma subscale items

Table 4 Results of bivariable and multivariable analysis of predictors of HIV medication adherence (linear regression)—N = 168

Variable	HIV medication adherence <sup>a</sup> bivari- able association (standard error)	HIV medication adherence <sup>a</sup> multivari- able coefficient (standard error)	Multivariable 95% confidence intervals
Internalized stigma (HIV Stigma Scale) <sup>b</sup>	5.61* (1.91)	4.90* (2.13)	(.69, 9.10)
Depressed (PHQ-9 cutoff)	-6.59* (3.01)	-6.64* (3.31)	(-12.54,65)
Male	3.01 (2.69)	1.65 (2.88)	(-4.03, 7.34)
Age 18–30	-3.63 (3.46)	1.61 (4.21)	(-6.78, 9.93)
Age 31–45	1.64 (2.97)	1.62 (3.14)	(-4.58, 7.82)
Disabled	03.75 (2.86)	-5.08 (3.05)	(-11.11, .95)
Illicit substance use last year	-3.98 (2.81)	-5.81* (2.90)	(-11.54,076)
African American	1.21 (3.39)	.83 (3.60)	(-6.26, 7.95)
Social support MOS Scale	.36 (1.25)	-2.20 (1.41)	(-4.98, .58)

\*p<.05

<sup>a</sup>Self-reported medication adherence was assessed using a visual analog scale<sup>32</sup>

<sup>b</sup>Higher score indicates lower levels of stigma

associated with poorer medication adherence and a higher HASI-P verbal abuse subscale score was also significantly associated with poorer HIV medication adherence. Anticipated stigma related to disclosure and perceived HIV stigma were not associated with HIV medication adherence.

## Multivariable Analysis (Tables 4, 5)

In logistic regression analysis, higher internalized stigma was associated with missing an HIV medical care appointment in the last 6 months (OR -.47, p=.013). Younger age, 18–30, was also associated with missing an HIV medical care appointment (OR 4.19, p=.011). Substance use,

depression, and other demographic and social characteristics were not associated with missed HIV medical care appointments.

Higher internalized stigma was also significantly associated with poorer HIV medication adherence in multivariable analysis (coefficient 4.90, p = .023). In addition, depression (coefficient – 6.64, p = .047) and illicit substance use (coefficient – 5.81, p = .047) demonstrated an association with medication adherence (p = .047 for each variable). None of the demographic or social characteristics were significantly associated with HIV medication adherence. Although there was a bivariable relationship of the personalized stigma subscale (measuring experienced stigma) with medication adherence, this relationship was not statistically significant in multivariable analysis. However, the HASI-P verbal abuse

Table 5 Results of bivariable and n	ultivariable analysis of missed HIV	V medical appointments (logistic regression)—N=163	j –
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Variable	Missed an HIV medical care appoint- ment in the last 6 months—bivariable analysis odd ratio (SE)	Missed an HIV medical care appoint- ment in last 6 months—multivariable analysis odds ratio (SE)	Multivariable 95% confidence interval	
Internalized stigma (HIV Stigma Scale) <sup>a</sup>	.59* (.14)	.47* (.14)	(.26, .85)	
Depressed (PHQ-9 cutoff)	.79 (.31)	.63 (.30)	(.36, 1.71)	
Male	1.76 (.61)	1.37 (.98)	(.61, 3.11)	
Age 18–30	2.85* (1.13)	4.19 (2.37)	(1.39, 12.70)	
Age 31–45	.91 (.34)	1.21 (.56)	(.49, 1.98)	
Disabled	1.21 (.43)	1.92 (.85)	(.81, 4.59)	
Illicit substance use last year	2.08* (.72)	1.80 (.73)	(.82, 3.97)	
African American	1.42 (.44)	1.67 (.98)	(.53, 5.27)	
Social support MOS Scale	1.06 (.17)	1.32 (.28)	(.88, 1.99)	

\*p<.05

<sup>a</sup>Higher score indicates lower levels of stigma

Table 6	Mediation of de	pression in the	relationship	of two type	s of stigma a	and medication adherence

	Internalized stigma coefficient (SE) (CI)	Verbal abuse stigma coefficient (SE) (CI)
Unadjusted bivariable association with adherence	5.61* (1.91)	-1.94* (.52)
	(1.83, 9.39)	(-2.96,92)
Unadjusted bivariable association with mediating variable (depression)	41* (.12)	1.24* (.44)
	(64, .18)	(.38, 2.11)
Association with adherence adjusted for confounders (total effect)	5.95* (2.12)	2.27* (.55)
	(1.77, 10.44)	(-3.37, -1.18)
Association with adherence adjusted for confounders and mediating variable (direct	4.90* (2.13)	2.23* (.56)
effect)	(.69, 9.10)	(-3.35, -1.12)

\*p<.05

subscale did show a statistically significant association with medication adherence in multivariable analysis (coefficient 2.23; p < .01; CI – 3.35, – 1.12), indicating that higher levels of verbal abuse related to HIV were associated with lower levels of medication adherence.

#### Mediation Findings (Table 6)

Mediation analysis examining whether depression acted as a mediator in the relationship of internalized stigma and HIV medication adherence revealed some evidence that depression is a mediator of this relationship. Following the criteria outlined by MacKinnon, this relationship met the mediation criteria of having a significant association of the independent variable (internalized stigma) with the dependent variable (adherence), a significant relationship of stigma to the hypothesized mediating variable (depression), a significant relationship of depression with adherence when both stigma and depression were included in the same model, and the coefficient relating stigma to adherence was shifted toward the null in the step 3 model (including the mediator) compared to the step 1 model with only stigma. However, internalized stigma continued to demonstrate a statistically significant relationship with adherence even when depression was included in the model suggesting that other pathways besides depression contribute to explaining the relationship of internalized stigma with HIV medication adherence.

Little evidence of mediation was identified for the relationship of the HASI-P verbal abuse related to HIV with HIV medication adherence. Although this relationship met the mediation criteria of having a significant association of the independent variable (verbal abuse) to the dependent variable (adherence) and a significant relationship of stigma to the hypothesized mediating variable, depression, a significant relationship of depression with adherence when both verbal abuse and depression were included in the same model was not identified, therefore the relationship did not meet the mediation criteria.

Depression was not significantly associated with missing a medical appointment for HIV medical care, thus this variable was not examined as a potential mediator in the relationship between stigma and missing a medical appointment.

# Discussion

The findings from this study of individuals living with HIV in the US Deep South identified substantial levels of internalized and experienced HIV-related stigma. For example, for experienced stigma, over one-third of the sample had experienced recent verbal abuse related to their HIV status and a similar proportion reported guilt due to their HIV status, an indication of internalized stigma. The finding regarding guilt due to HIV status is similar to the finding identified with a similar question in the national Medical Monitoring Project (MMP) cohort of individuals living with HIV. Regional differences were not explored in the MMP so it is not clear whether internalized stigma was different in the seven southern states than the nine other states included in the MMP project [38]. A few studies have identified higher levels of HIV-related stigma in the US South but more comprehensive study is needed to adequately examine regional differences in internalized stigma.

Study findings indicated that internalized HIV-related stigma and recent verbal abuse experiences regarding HIV status were associated with poorer HIV medication adherence among the sample of individuals living with HIV in the US Deep South. Perceived community stigma and anticipated stigma related to disclosure were not found to be significantly associated with medication adherence. Similar to findings from previous studies, depression was also associated with poorer HIV medication adherence [39].

Mediation analysis found that depression may represent one of the pathways through which internalized stigma influences adherence but that a relationship between internalized stigma and adherence remained after accounting for depression, suggesting that internalized stigma may also have an independent effect on medication adherence. However, due to the cross-sectional structure of this study, the findings must be considered exploratory with additional longitudinal study needed for confirmation.

Internalized stigma was significantly associated with having missed at least one appointment for HIV medical care in the last 6 months. Younger age was also associated with missing an appointment but depression and recent higher HIV-related verbal abuse were not predictive of missed appointments. Depressive symptoms and experiencing HIV-related verbal abuse may have a greater influence on adherence than on attending medical visits, as they may interfere with the planning and intent necessary for daily medication use. Additional study is needed to gain a better understanding of how internalized stigma influences health care outcomes and what factors influence internalized stigma in order to further inform the development of interventions to address this form of stigma.

The findings of this study must be considered in the context of the study limitations including the cross-sectional design, which does not allow for conclusions regarding the direction of relationships of internalized stigma and stigma experiences with medication and medical visit adherence. However, it seems less likely that medication adherence and medical visits predict stigma, suggesting the influence of HIV-related stigma on these health care outcomes. In addition, both medical appointment attendance and medication adherence were measured through self-report, which may be influenced by poor recall and/or social desirability bias. Finally, the study findings may not be generalizable to individuals not receiving medical care for HIV, as the majority of the participants were recruited from medical clinics.

## Conclusions

Despite the study limitations, the findings of this study provide insight into the high levels of HIV-related stigma in the Deep South and the negative association of internalized stigma and recent stigma experiences on health care outcomes. These findings suggest the need to identify and develop effective interventions to address internalized stigma to improve these outcomes. These interventions must consider the specific cultural factors in the Deep South that likely influence HIV-related stigma including sexual orientation stigma, religiosity, poverty, racism, and education [1]. Some potential interventions to address HIV-related stigma have been documented in the research literature. Stangl et al. [12] reviewed stigma reduction interventions in the published literature including an intervention by Rao et al., the Unity Workshop, that provided education and skill-building in coping with and abating HIV-related stigma among individuals living with HIV and showed a reduction in internalized stigma [40]. The workshop was facilitated by peer educators and was designed to be experiential rather than didactic. Another intervention that has shown some effectiveness in reducing stigma is the Finding Respect and Ending Stigma around HIV (FRESH) intervention, which involves individuals living with HIV and health care providers participating together in an interactive stigma reduction training [41]. This type of intervention is important to implement in the South, where cultural views around HIV and sexuality may contribute to greater stigma among care providers. Successful interventions such as these can be adapted with input from individuals living with HIV in the South to reduce the negative effects of HIV-related stigma experiences. In addition, identifying interventions that are successful in increasing community-level HIV education and reducing community level stigma is critical to reduce stigmatizing experiences for people living with HIV.

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## **Compliance with Ethical Standards**

**Conflict of interest** The authors declare that they have no conflict of interest.

**Ethical Approval** All procedures performed in studies involving human participants were in accordance with the ethical standards of the Duke Medical Center institutional review board and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

**Informed Consent** Informed consent was obtained from all individual participants included in the study.

## References

- 1. Reif S, Safley D, McAllaster C, Wilson E, Whetten K. State of HIV in the US Deep South. J Community Health. 2017;42(5):844–53.
- NCHHSTP Atlas. 2016. http://www.cdc.gov/nchhstp/atlas/. Accessed 1 June 2019.
- Kaiser Family Foundation. State Health Facts: Poverty Rate by Age. 2017. http://kff.org/other/state-indicator/povertyrate-by-age/?currentTimeframe=0&sortModel=%7B%22col Id%22:%22Total%22,%22sort%22:%22desc%22%7D. Accessed 14 July 2019.
- Gilman B, Bouchery E, Hogan P, Negrusa S, Trent-Adams S, Cheever L. The HIV clinician workforce in the United States. HIV Spec. 2016;8(3):2–9.
- Heumann C, Cohn S, Krishnan S, et al. Regional variation in HIV clinical trials participation in the United States. South Med J. 2015;108(2):107–16.
- National Alliance of State and Territorial AIDS Directors. Stigma and the Impact on Public Health. Ryan White HIV/AIDS Program Grantee Meeting. Washington DC; 2012.
- Kerr J, Valois R, DiClemente R, et al. HIV-related stigma among African-American youth in the northeast and southeast US. AIDS Behav. 2014;18:1063–7.
- Reif S, Sullivan K, Wilson E, Berger M.: HIV/AIDS Care and Prevention Infrastructure in the US Deep South. 2016. https:// southernaids.files.wordpress.com/2016/03/hiv-aids-care-andprevention-infrastructure-in-the-u-s-deep-south1.pdf. Accessed 1 Sept 2018.
- Sweeney S, Vanable P. The association of HIV-related stigma to HIV medication adherence: a systematic review and synthesis of the literature. AIDS Behav. 2016;20:29–50.
- Turan B, Budhwani H, Fazeli P, et al. How does stigma affect people living with HIV? The mediating roles of internalized and anticipated HIV stigma in the effects of perceived community stigma on health and psychosocial outcomes. AIDS Behav. 2017;21:283–91.

- Waite K, Paasche-Orlow M, Rintamaki L, Davis T, Wolf M. Literacy, social stigma and HIV medication adherence. J Gen Intern Med. 2008;23(9):1367–72.
- Stangl A, Brady L, Fritz K. Measuring HIV stigma and discrimination. 2012. http://strive.lshtm.ac.uk/system/files/attachments/ STRIVE%20stigma%20measurement.pdf. Accessed 14 July 2019.
- Earnshaw V, Chaudoir S. From conceptualizing to measuring HIV stigma: a review of HIV stigma mechanim measures. AIDS Behav. 2009;13(6):1160–77.
- Earnshaw V, Smith L, Chaudoir S, Amico K, Copenhaver M. HIV stigma mechanisms and well-being among PLWH: a test of the HIV stigma framework. AIDS Behav. 2013;17(5):1785–95.
- White J, Gordon J, Mimiaga J. The role of substance use and mental health problems in medication adherence among HIV-infected MSM. LGBT Health. 2014;1(4):319–22.
- Chitsaz E, Meyer J, Krishman A, Springer S, Marcus R, Zaller N. Contribution of substance use disorders on HIV treatment outcomes and antiretroviral medication adherence among HIVinfected persons entering jail. AIDS Behav. 2013;17(Supplement 2):118–27.
- Gonzalez J, Batchelder A, Psaros C, Safren S. Depression and HIV/AIDS treatment nonadherence: a review and meta-analysis. J Acquir Immune Defic Syndr. 2011;58(2):181–7.
- Rao D, Feldmans B, Fredricksen R, Crane P, Simoni J, Kitahata M. A structural equation model of HIV-related stigma, depressive symptoms, and medication adherene. AIDS Behav. 2012;16(3):711–6.
- Sayles J, Wong M, Kinsler J, Martings D, Cunningham W. The association of stigma with self-reported access to medical care and antiretroviral therapy adherence in persons living with HIV/ AIDS. J Gen Intern Med. 2009;24(10):1101–8.
- Mitzel L, Vanable P, Brown J, Bostwick R, Sweeney S, Carey M. Depressive symptoms mediate the effect of HIV-related stigmatization on medication adherence among HIV-infected men who have sex with men. AIDS Behav. 2015;19(8):1454–9.
- Harvey P. Race, culture, and religion in the American South. Oxford research encyclopedia of religion. Oxford: Oxford University Press; 2015.
- Brunn S, Webster G, Archer J, Reif S. The bible belt in a changing south:shrinking, relocating and multiple buckes, vol. 51. Chapel Hill: The University of North Carolina Press; 2011. p. 513–49.
- 23. Pew Research Center. Religious landscape study. Washington: Pew Research Center; 2014.
- Reif S, Wilson E, McAllaster C. Perceptions and impact of HIV stigma among high risk populations in the US Deep South. J HIV AIDS. 2018. https://doi.org/10.16966/2380-5536.
- 25. O'Connell H. The impact of slavery on racial inequality in poverty in the contemporary US South. Soc Forces. 2012;90(3):713–34.
- Acharyn A, Blackwell M, Sen M. The political legacy of American slavery. J Polit. 2016;78(3):621–41.
- Adimora A, Schoenback V, Doherty I. HIV and African Americans in the southern United States: sexual networks and social context. Sex Transm Dis. 2006;33(7):39–45.
- Berger B, Ferrans C, Lashley F. Measuring stigma in people with HIV: psychometric assessment of the HIV Stigma Scale. Res Nurs Health. 2001;24(6):518–29.
- Buseh A, Keber S, Hewitt J, Stevens P. Perceived stigma and life satisfaction: experiences of urban African-American men living with HIV/AIDS. Int J Men's Health. 2006;5(1):35–51.
- Holzemer W, Uys L, Chirwa M, et al. Validation of the HIV/ AIDS Stigma Instrument - PLWA (HASI-P). AIDS Care. 2007;19(8):1002–12.
- Nunnally C, Bernstein I. Psychometric theory. 3rd ed. New York: McGraw-Hill; 1994.
- 32. Kalichman S, Amaral CM, Swetzes C, et al. A simple singleitem rating scale to measure medication adherence: further

evidence for convergent validity. J Int Assoc Phys AIDS Care. 2009;8(6):367-74.

- Sherbourne C, Stewart A. The MOS social support survey. Soc Sci Med. 1991;32:705–14.
- 34. Kroenke K, Spitzer R, Williams J. The PHQ-9: validity of a brief depression severity measure. J Gen Intern Med. 2001;16(9):606–13.
- Smith P, Schmidt S, Allensworth-Davies D, Saitz R. A singlequestion screening test for drug use in primary care. Arch Intern Med. 2010;170(13):1155–60.
- MacKinnon D. Mediation analysis. Ann Rev Psychol. 2007;58:593-614.
- Baron R, Kenny D. The moderator-mediator variable distinction in social psychological research: conceptual, strategic, and statistical considerations. J Pers Soc Psychol. 1986;51:1173–82.
- Baugher A, Beer L, Fagan J, et al. Prevalence of internalized HIVrelated stigma among HIV-infected adults in care, United States, 2011–2013. AIDS Behav. 2017;21(9):2600–8.

- Gonzalez J, Batchelder A, Psaros C, Safren S. Depression and HIV/AIDS treatment nonadherence: a review and meta-analysis. J Acquir Immune Defic Syndr. 2013;58(2):181–7.
- 40. Rao D, Desmond M, Andrasik M, et al. Feasibility, acceptability, and preliminary efficacy of the unity workshop: an internalized stigma reduction intervenion for African American women living with HIV. AIDS Patient Care STDs. 2012;26(10):614–20.
- 41. Batey D, Whitfield D, Mulla M, et al. Intervention to reduce HIVrelated stigma among healthcare workers in the United States: piloting of the FRESH Workshop. AIDS Patient Care STDs. 2016;30(11):519–27.

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