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Investigating changes in internalized stigma and avoidant coping among African American adults living with HIV and serious mental illness following a peer-led intervention

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ABSTRACT

Background: Individuals living with HIV navigate the health implications of HIV and HIV discrimination. This study aimed to examine changes in internalized stigma and avoidant coping among African American adults living with HIV and serious mental illness (SMI) following a peer-led intervention.

Methods: In this quasi-experimental study, 16 patients were recruited using convenience sampling from an HIV clinic in an urban hospital setting in the United States for a community-based participatory research (CBPR) developed peer-led intervention pilot. Participants answered questions about their experiences of HIV-related discrimination, internalized stigma, and cognitive escape coping before and after participating in four 90-minute peer-led weekly group sessions. For data analysis, paired-samples t-test and linear regression with Hayes' PROCESS Macro in SPSS 27 were used at a 5% significance level.

Results: There was a significant indirect effect of HIV-related discrimination on cognitive escape coping through internalized stigma (b = 0.28, 95% CI [0.03, 0.61]). Post-intervention non-significant associations suggest that a CBPR-developed peer-led intervention may buffer against the effects of HIV-related discrimination.

Conclusion: Our study provides initial support that community and peer support approaches may buffer against the effects of discrimination on internalized stigma and avoidant coping among African American individuals living with HIV and SMI.

Keywords: African Americans, HIV, Community-Based Participatory Research, Social Stigma

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Introduction

African American individuals in the United States (U.S.) face many health disparities compared to other racial/ethnic groups in the U.S. (1). One particularly stark disparity occurs in the realm of HIV, where African Americans are affected disproportionately. For example, despite accounting for only 13% of the U.S. population, African Americans comprised 42% of new U.S. HIV diagnoses in 2018 (1). African Americans also disproportionately account for more HIV/AIDS related morbidity and mortality than White Americans, with the death rate being 20.5 per 1,000 persons, 13% higher than the rate for White individuals (2).

These disparities in physical and HIV health largely relate to stigma and discrimination. African American individuals have long faced racial discrimination in the U.S. (3), with significant negative implications for their health (1). African American individuals living with HIV, consistent with the general population of individuals living with HIV, may additionally experience HIV-related discrimination, which is inequitable treatment based on their HIV status (1,4). Experiencing discrimination broadly, and HIV-related discrimination specifically, can relate to internalized stigma. Internalized stigma occurs when someone comes to believe they are inferior to others because of the discrimination they have experienced from others (5). African American individuals who are living with HIV, experiencing HIV-related discrimination from others, and feeling internalized stigma about having HIV, may use coping strategies to manage their stress.

A number of coping strategies can be used to alleviate stress associated with HIV-related discrimination and internalized stigma. Some strategies, known as "approach coping" strategies, may be effective both in the short-term and long-term. These include establishing a social support network (6) and treatment team (7). Other strategies, known as "avoidant coping" strategies, may be effective in the short-term but unhealthy in the long-term. For example, substance use (8) and cognitive escape (9) strategies may facilitate individuals temporarily "escaping" from their stressful circumstances, however these strategies do not address the underlying stress directly. Examples of cognitive escape strategies include thought suppression (10) and distraction from the problem (11). Using cognitive escape strategies broadly relates to experiencing discrimination and stigma among people living with HIV (12). For example, in a longitudinal study by Earnshaw and colleagues, a large South African sample of people living with HIV were measured on their internalized stigma, avoidant coping, and antiretroviral adherence over one year (12). Longitudinal structural equation modeling showed avoidant coping mediated the relation between internalized stigma and antiretroviral adherence. This provides evidence for the association between internalized stigma and medication adherence through avoidant coping; however, no known study tests the mechanisms by which HIV-related discrimination relates to internalized stigma and cognitive escape. It is important to test such models because it elucidates the pathways by which HIV-related discrimination may lead to avoidant coping and subsequent negative health outcomes.

Peer support, and interventions that cultivate peer support, may be a source of resilience for African American individuals. For example, the implementation of a peer-led, empowerment-based intervention was seen to improve cardiovascular disease risk factors among African American adults (13). As another example, peer-led community-based interventions have shown to promote dietary changes and physical activity among African American individuals (14). Peer support also inversely relates to experiences of discrimination (15), internalized stigma (16), and ineffective coping strategies (17). Given these bivariate associations between peer support, discrimination, and stigma, it is reasonable to think peer support also may attenuate associations between HIV-related discrimination, internalized stigma, and cognitive escape coping.

The current study has two aims. First, we aim to test an empirical model in which internalized stigma

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mediates the relation between HIV-related discrimination and cognitive escape. To test this model, we used baseline data from a pilot, peer support intervention aiming to increase treatment engagement among African Americans living with HIV and serious mental illness. The second aim tested the same model post-intervention, thereby assessing whether model associations were attenuated after participation in the peer support intervention. This mediation model is consistent with the Minority Stress Model, which posits that distal stressors (e.g., discrimination) relates to proximal stressors (e.g., internalized stigma), which themselves relate to coping (e.g., cognitive escape) (18). This model is appropriate to test among African American individuals in the U.S., given that this group is known to experience relatively poor health related to racial discrimination (3).

Methods

This quasi-experimental study was a secondary analysis of a community-based participatory research (CBPR) study conducted in Chicago, IL that developed a peer-led pilot intervention (Prepare2Thrive) published here (19,20). We consider the intervention peer-led because three CBPR team members with lived-experience led the intervention (i.e., two Black/African American men living with HIV and serious mental illness [SMI], one Black/African American woman living with SMI). Procedures are described briefly here; additional detail regarding procedures are available in the intervention development and main intervention outcomes publications, respectively (19,20). The study was approved by the Illinois Institute of Technology's Institutional Review Board.

Participants and procedures:

Participants were recruited using posted advertisements and by staff referral at a Ryan White-funded HIV clinic housed in a midwestern metropolitan U.S. city hospital. Participants answered questions about their demographics and health history on a brief screening questionnaire created by the research team. Interested individuals could access the screening questions via a link provided on the study advertisement or in-person on a tablet device at the recruitment site assisted by study personnel. Forty-two respondents completed the eligibility screening questionnaire, of which 22 were eligible. Eligible participants a) were 18 years of age or older, b) identified their race/ethnicity as African American (participants of multiple race/ethnic identities were included if at least one of the identities selected was African American), c) could understand English, d) lived in the metropolitan area served by the HIV clinic, e) had an HIV-positive diagnosis, and f) reported current symptoms of serious mental illness (SMI). Participants must have also reported sub-optimal treatment engagement defined as: 1) missed a dose of any medication within the past 3 months, 2) missed a medical appointment within the past year, or 3) missed a psychotherapy appointment within the past year. SMI was assessed by participants indicating that their life had been currently affected by emotional problems and at least two areas of functioning were affected by their emotional problems. This assessment was designed to include participants who may be experiencing SMI symptoms but not be aware of a diagnosis. These broad inclusion criteria are consistent with a similar study in a group setting in an a community clinic with a majority African American sample (21). Participants who met screening criteria were contacted by trained study personnel within three days to schedule the pre-intervention assessment. Four participants were lost-to-follow-up (6 weeks) from screening to completion of the baseline questionnaire, thus 18 participants completed the pre-intervention assessment. Two additional participants were lost-to-follow-up after completion of the pre-intervention assessment and did not participate in the intervention. Due to time and budgetary constraints, recruitment concluded after six weeks.

Participants filled out a set of questionnaires at the recruitment site before and after participating in four 90-minute peer-led weekly group intervention sessions. Trained study personnel reviewed with participants the study procedures, risks, benefits, site contact information, the nature of

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confidentiality and voluntary participation, and the reimbursement schedule as outlined on the voluntary informed consent form before completing the pre-intervention measures. Study personnel ensured participant comprehension of the consent form content, specifically by assessing for understanding of key parts of the consent form and answering any participant questions. After obtaining informed consent, participants completed study questionnaires using either a tablet or computer. Participants were paid with a $20 bank gift card for pre- and post-intervention assessment. Participants were also paid $25 for each intervention session attended.

Measures

HIV-related Discrimination. HIV-related discrimination was measured using the HIV/AIDS Stigma Instrument – PLWA (HASI-P). The HASI-P measures perceived stigma and is appropriate for measuring changes in stigma over time. The measure includes six subscales: Verbal Abuse (8 items, α = 0.89); Negative Self-Perception (5 items, α = 0.906); Health Care Neglect (7 items, α = 0.832); Social Isolation (5 items, α = 0.890); Fear of Contagion (6 items, α = 0.795); and Workplace Stigma (2 items, α = 0.758). For each item, respondents are asked, "In the past three months, how often did the following events happen because of your HIV status?" Response options are given on a four-point Likert-scale (0 = "never" to 3 = "most of the time"). For the current study, a total score was used with Negative Self-Perception subscale removed, to capture perceived discrimination from external sources, rather than internalized or self-stigma. The measure has adequate content and construct validity (60.72% explained variance), modest concurrent validity with HIV-related quality of life (physical health r = -.28, p < .001, mental health r = -.36, p < .001) and frequency and intensity of common signs and symptoms experienced by persons living with HIV (r = .36, p < .001), and acceptable internal consistency reliability for each of the six subscales (see above) and total score (α = .94) in prior studies (22,23). The measure had good internal consistency in the current study (pre α = .89; post α = .95).

Internalized Stigma. Internalized stigma was measured using the *self-blame subscale* of the Brief COPE (24). The Brief COPE is a 28-item questionnaire assessing 14 types of coping strategies: active coping, planning, positive reframing, acceptance, humor, religion, using emotional support, using instrumental support, self-distraction, denial, venting, substance use, behavioral disengagement, and self-blame. Items for the self-blame subscale are "I've been criticizing myself" and "I've been blaming myself for things that happened." Responses are given on a four-point Likert-scale (1 = "I usually don't do this at all" to 4 = "I usually do this a lot"). The subscale has demonstrated adequate internal consistency (α = .69)(24). The internal consistency for the current study was adequate (pre α = .78; post α = .49).

Cognitive Escape. Cognitive escape was measured using the *thought suppression/distraction subscale* of the Cognitive Escape Scale (CES). The CES is a measure of HIV-related cognitive avoidance (25). The thought suppression subscale consists of five items answered on a five-point Likert-scale (1 = "Never" to 5 = "Always"). Participants are asked, "How often do you": 1) "Just try to put HIV/AIDS out of your mind?"; 2) "Get tired of being concerned about HIV/AIDS?"; 3) "Need a 'vacation' from HIV/AIDS?"; 4) "Not want to think about HIV/AIDS anymore?"; 5) "Just try to focus on the day to day things in your life when the thought of HIV/AIDS comes to mind?" This subscale has demonstrated adequate construct validity (variance explained = 10%) and internal consistency (α = .80), as well as concurrent validity with measures of HIV-related worry (r = .48, p < .01), depression (r = .31, p < .05) and perceived stress (r = .29, p < .01) in prior research (25). Internal consistency for the current study was acceptable (pre α = .87; post α = .84).

Statistical analysis

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We ran two mediation models total – one model at baseline and the same model at post-intervention. These two models were run instead of running a moderated mediation testing an interaction effect of time, because this was a pilot study and our relatively low sample size precluded the statistical power to test the moderated mediation models. The first model tested the relation between HIV discrimination and cognitive escape, mediated by internalized stigma, at pre-intervention. The second model tested the same associations at post-intervention. Means and standard deviations are presented on variables of interest pre- and post-intervention. Paired-samples t-tests were used to examine differences between pre- and post-intervention scores on variables of interest. Analyses were conducted using linear regression and bootstrapped confidence intervals in the PROCESS macro developed by Hayes in SPSS 27 (26). Significance level was set at 5%.

Results

Demographics information for the 18 total participants are presented in Table 1. Most participants were middle-aged, with a mean age of 46.83 (*SD* = 11.00). All participants identified as African American/Black, with one participant identifying as both African American/Black and Puerto Rican. Most participants reported that they identified as Gay or Lesbian (*n*=8, 44.4%) and male (*n*=14, 77.8%).

Results of paired samples t-tests are presented in Table 2. Notably, from pre-intervention to post-intervention, mean scores of HIV discrimination decreased but this was not significant (t = -.19, p = .849) and cognitive escape significantly decreased (t = 4.62, p < .001).

Table 1. Demographics information of study participants

Variable	*N*(%)	Variable	*N*(%)
Gender Identity		Religious Preference	
Male	14(77.8)	Christian/Protestant	6(33.3)
Female	4(22.2)	Baptist	5(27.8)
Transexual	1(5.6)	None	5(27.8)
Sexual Orientation		Roman Catholic	1(5.6)
Heterosexual	6(33.3)	Agnostic	1(5.6)
Gay or Lesbian	8(44.4)	Not religious, but spiritual	1(5.6)
Bisexual	3(16.7)	Mental Health Diagnoses	
Not sure/Don't know	2(11.1)	Bipolar Disorder	3(18.75)
Relationship Status		Anxiety	2(12.5)
Single (never married)	16(88.9)	Major Depressive Disorder	2(12.5)
In a committed relationship	1(5.6)	Schizophrenia	2(12.5)
Divorced	1(5.6)	OCD	1(6.3)
Work Status		PTSD	1(6.3)
On disability	10(55.6)	Schizoaffective Disorder	1(6.3)
Not employed	4(22.2)	Phobia	1(6.3)
Full-time employed	3(16.7)	Don't Know	2(12.5)
Part-time employed	1(5.6)		
Graduate student	1(5.6)		

Note. For gender identity, authors gave several response options including e.g., transgender woman, transgender man, non-binary, genderqueer; one participant self-reported that they identified as "transexual." OCD indicates Obsessive Compulsive Disorder. PTSD indicates Post-traumatic Stress Disorder. In some categories, the total may be greater than 18, as participants selected multiple response options within each category.

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Table 2. Comparing HIV Discrimination, Internalized Stigma, and Cognitive Escape before and after of intervention

Study variables	Pre-intervention			Post-intervention			*t*-test	*p*
	M	*SD*	*range*	*M*	*SD*	*range*		
HIV discrimination	7.86	2.80	5.00-13.00	7.57	3.21	5.00-14.78	-0.19	0.849
Internalized stigma	2.13	1.14	1.00-4.00	2.13	0.76	1.00-3.50	0.00	1.00
Cognitive escape	3.57	1.20	1.00-5.00	2.92	1.16	1.00-5.00	4.62	<.001

Note. N = 16 participants that provided complete pre- and post-data. Two participants missing post-intervention data were removed from these analyses.

Mediation Analyses

Results of the mediation analyses are presented in Table 3.

Model at pre-intervention: Testing internalized stigma as a mediator of the association between HIV discrimination and cognitive escape coping at pre-intervention. At pre-intervention, we hypothesized that experiencing greater HIV discrimination would predict an increase in cognitive escape coping, and that this association would be mediated by internalized stigma. At pre-intervention, HIV discrimination was negatively associated with cognitive escape related coping, and the association was non-significant (b = -0.22, p = .43). However, consistent with study hypotheses, there was a significant indirect effect of HIV discrimination on cognitive escape coping through internalized stigma b = 0.28, 95% BCa CI [0.03, 0.61]. Thus, partial mediation occurred.

Additionally, we hypothesized that internalized stigma would be positively associated with both HIV discrimination and cognitive escape coping at pre-intervention. We observed a positive association between internalized stigma and both HIV discrimination (b = .52, p = .027) and cognitive escape coping (b = .54, p = .061); however, only the association between HIV discrimination and internalized stigma was significant (p = .03), whereas the association between self-stigma and cognitive escape coping was approaching significance (p = .06).

Model at post-intervention: Testing internalized stigma as a mediator of the association between HIV discrimination and cognitive escape coping at post-intervention. We hypothesized that the association between HIV discrimination and cognitive escape coping would no longer be significant at post intervention, and that internalized stigma would no longer serve as a mediator in the association between HIV discrimination and cognitive escape coping. These hypotheses were supported, results of multiple linear regression showed there was a relation between HIV discrimination and cognitive escape coping which was not significant (b = -0.16, p = .57) and there was no evidence of mediation (b = 0.01, 95% BCa CI [-0.08, 0.30]).

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Table 3. Results of testing internalized stigma as a mediator of the association between HIV discrimination and cognitive escape coping at pre- and post-intervention

Variable	*b*	95% *CI*	SE b	β	*F*	R^2	*p*
Pre-intervention							
Step 1					5.92	.27	.027*
Constant	.67	[-.86-2.20]	.72				.367
HIV discrimination-internalized stigma	.21	[.03-.40]	.09	.52			.027*
Step 2					2.09	.22	.158
Constant	2.96	[1.17-4.75]	.84				.003*
HIV discrimination-cognitive escape	-.09	[-.34-.15]	.12	-.22			.432
Internalized stigma-cognitive escape	.57	[-.03-1.18]	.28	.54			
Direct effect of X on Y	-.09	[-.33-.15]	.12				
Indirect effect of X on Y	.12	[.01-.31]*	.08				
Post-intervention							
Step 1					.12	.01	.736
Constant	1.96	[.85-3.07]	.52				.002*
HIV discrimination-internalized stigma	.02	[-.11-.16]	.06	.09			.736
Step 2					.20	.03	.818
HIV discrimination-internalized stigma	-.05	[-.25-.15]	.09	-.16			.571
Internalized stigma-cognitive escape	.12	[-.72-.96]	.39	.09			.756
Direct effect of X on Y	-.05	[-.25-.15]	.09				.571
Indirect effect of X on Y	.002	[-.03-.10]	.03				

Note. CI = Confidence interval. Confidence intervals are constructed using 5,000 bootstrapped samples. * indicates significance at $p < .05$.

Discussion

Study findings indicate a community support intervention may have attenuated associations between HIV discrimination and cognitive escape, HIV discrimination and internalized stigma, and internalized stigma and cognitive escape. Thus, while we cannot eliminate discrimination, a community support intervention can reduce the effects of discrimination on the way a person sees themselves, and the way a person copes with discrimination.

Related recent work using an experience sampling method indicated that for non-substance using men living with HIV, daily experiences of discrimination was related to increases in subsequent ratings of internalized HIV stigma (27). This work provides evidence of state-level associations between experiences of discrimination and internalized stigma, and suggests that state-level interventions may be appropriate to reduce the effects of discrimination on internalized stigma. Another recent study of nearly 200 participants recruited from an HIV clinic in the southeastern U.S. found that HIV-related discrimination was associated with alcohol use severity, with this association mediated by internalized HIV stigma (28). Researchers have long proposed that alcohol use can be used as a means of cognitive escape from stress related to HIV (29), and empirical work supports this notion (9).

This study is framed by Minority Stress theory, which is appropriately and frequently used in the health equity literature (30). We also borrow from the framework of Intersectionality (31), which states that individuals at the intersection of multiple systems of oppression face more barriers to health and well-being than do those who experience one or zero systems of oppression. Extant empirical work combining Minority Stress and Intersectionality is limited, although it has been done recently among, e.g., LGBTQ+ Latino/a young people (32), and Latinx and African American sexual minority women (33). We believe that using an "Intersectional Minority Stress" framework is becoming increasingly useful, and even necessary, as we strive to understand and reduce health inequities among those who most consistently face health disparities (34).

Future Directions

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Future research should aim to replicate the design and implementation of peer support interventions. This literature is still relatively limited and currently focuses on feasibility and acceptability (35), whereas it would be helpful to support and conduct larger comparative effectiveness studies that test peer support models versus treatment-as-usual approaches. Regarding future clinical work, our results suggest that individual- and group-level therapy among African American individuals living with HIV and SMI should include focus on experiences of discrimination, internalization of stigma, and escape coping; and, on the associations between these. Regarding policy implications, our results suggest that African American individuals living with HIV and SMI would benefit from state- and federal-level legislation providing funding for community-based and/or peer-led interventions.

Regarding study strengths, this study used multiple relevant theories to inform intervention development and study analyses. The study sample is a strength as African American individuals have been underrepresented in health research (36). Next, the original pilot study used CBPR in its design, implementation, and data analysis (19,20), consistent with recent calls for research approaches that engender community participation (37). One potential study limitation is in our analytic approach: Consistent with other pilot studies and due to a relatively small sample size and related low power, we did not test for a time x intervention interaction effect (38). Instead, we ran two separate mediation models. Additionally, the reliability of our internalized stigma measure was relatively low post-intervention compared to pre-intervention. Notably, this subscale included only two items; thus, a more robust assessment of this construct would have been useful. Finally, there was no control group in the original pilot intervention. Analyzing comparative, control group data would be a more robust test of intervention effects.

Conclusion

Community and peer support interventions may buffer against the effects of discrimination on both internalized stigma and avoidant coping, among African American individuals living with HIV and SMI. These findings are important insofar as, while eliminating discrimination may be impossible, interventions such as ours may help reduce the effects of discrimination on negative self-perception and ineffective coping.

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Conflict of interest

All authors declare we have no personal or financial conflicts of interest to report. We take complete responsibility for the integrity and accuracy of the data.

Authors’ contribution

All authors contributed to the study conception and design. Material preparation, data collection and analysis were performed by Arryn A. Guy, Honor Woodward, and Steff Du Bois. The first draft of the manuscript was written by Arryn A. Guy, Honor Woodward, Lynn Kannout, and Steff Du Bois. All authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

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