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Exploring the Impact of Experiences with Everyday and Major Discrimination and HIV-Related Stigma on Engagement in HIV Care Among Older African Americans Living with HIV

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Abstract

Objectives The purpose of this pilot study was to explore the effect of HIV-related stigma and everyday major experiences of discrimination on medication and clinic visit adherence among older African Americans living with HIV in Ohio.

Methods We collected data from 53 individuals who were living with HIV in Ohio, ≥ 50 years of age, and who identified as Black or African American. We conducted logistic regression models to examine the impact of HIV-related stigma and experiences of discrimination on medication and visit adherence. Each model controlled for age, time since diagnosis, and sexual orientation.

Results The average age was 53.6 ± 2.1 years and 94.3% were men. Almost half (49.1%) of the participants reported poor medication adherence and almost a third (31.4%) reported poor visit adherence. HIV-related stigma (adjusted odds ratio (aOR) = 1.39; 95% confidence interval (CI) = 1.02–1.89) and major experiences of discrimination (aOR = 1.70; 95% CI = 1.11–2.60) were associated with a greater odds of poor medication adherence. Additionally, major experiences of discrimination were associated with a threefold increase in the odds of poor visit adherence (aOR = 3.24; 95% CI = 1.38–7.64).

Conclusions HIV-related stigma and major experiences of discrimination impede optimal medication and HIV clinic visit adherence for older African Americans living with HIV. To reduce the impact of stigma and discrimination on HIV care engagement, our first step must be in understanding how intersecting forms of stigma and discrimination impact engagement among older African Americans living with HIV.

Keywords HIV · Stigma · Discrimination · Visit adherence · Medication adherence

Introduction

In the USA, older adults (≥ 50 years) make up 17% of all new HIV cases and over half (51%) of people living with HIV (PLWH) are 50 years of age and older [1, 2]. The increases in the population of older PLWH can be attributed to advances in HIV medication that have allowed PLWH to live longer and healthier lives. Pharmacological advances do not tell the whole story, however, as thousands of adults aged ≥ 50 are diagnosed with HIV every year [2]. Although older adults have the same risk factors (e.g., injection drug use) as their younger counterparts, they are more likely to have a late diagnosis due to a perception that older adults are at a lower risk for exposure [3]. Furthermore, the burden of risk is not equally distributed across older adults; racial/ethnic disparities in HIV are still evident. Older African Americans are disproportionately impacted by HIV and have the most severe HIV burden compared to other racial and ethnic groups [2]. African Americans comprise 42% of all new diagnoses among older adults and make up 39% of all older PLWH [2]. Moreover, older African Americans living with HIV are consistently less likely to be engaged along the HIV care continuum (i.e., linked to medication, and virally suppressed) [3, 4], which may explain the disparities.

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Engagement along the HIV care continuum is beneficial to living a healthier and longer life and reducing the risk of transmission. Yet, stigma undermines participation in all facets of the HIV care continuum [5–14]. Older PLWH experience stigma through processes of rejection, stereotyping, fear of contagion, violations of confidentiality, social isolation, and internalized ageism, and this in turn affects engagement [15–19]. For instance, HIV-related stigma has been shown to be a major barrier to engagement along the HIV care continuum; specifically, it negatively influences rates of retention in care and medication adherence [7, 20, 21]. Although older PLWH do not appear to experience higher levels of HIV-related stigma compared to their younger counterparts [22], older African American PLWH appear to be particularly vulnerable to HIV-related stigma [8, 23–25]. In other words, the experiences or anticipations of the stigma that impact engagement in care are not universal, but are shaped by intersecting strands of identity constructed not only by HIV status, but by factors such as race, gender, and age.

In order to understand the specific mechanisms through which stigma impacts care engagement, researchers have turned to focus on the different subtypes of HIV-related stigma [6]. The HIV Stigma Framework suggests that enacted HIV stigma (actual experiences of discrimination by others), anticipated HIV stigma (expectations that they will be treated negatively in the future), and internalized HIV stigma (internal endorsements of negative thoughts about HIV) each play a separate role in impacting HIV care engagement [6]. Anticipated and internalized stigma have been shown to negatively impact visit [13, 26] and medication adherence [26, 27]. In addition to HIV-related stigma, researchers have suggested the need to further understand how HIV-related stigma intersects with other forms of discrimination like racism, sexism, and ageism [28–32].

Extensive research has been conducted to show how perceived discrimination can negatively affect health and health care utilization [33, 34]. Most researchers have shown that increased experiences of discrimination were associated with delays in seeking care and poor adherence to medications. This connection may be due to discrimination's impact on medical mistrust and satisfaction with the health care system [34].

Several studies have examined the impact of discrimination on HIV care outcomes [35–43]. A review of qualitative studies found that perceived discrimination was associated with poor medication adherence among PLWH [44]. Cressman et al. [39] examined the relationship between discrimination and missed HIV appointment visits among women living with HIV and whether that relationship was moderated by race/ethnicity. The authors found that higher levels of experiences of discrimination were associated with a higher prevalence of missed appointments. However, race/ethnicity did not moderate the relationship [39]. Discrimination has been shown to also affect medication adherence directly as well as indirectly through factors like medical mistrust and depressive symptoms. Relf et al. [43] suggested that among women living with HIV in the south, experiences of everyday discrimination indirectly impacted medication adherence through depressive symptoms. Additionally, Galvan et al. [36] showed that experiences of discrimination due to Latino ethnicity led to medical mistrust which then led to poor medication adherence.

Although there is a growing body of literature showing the impact of stigma and discrimination on HIV care outcomes, like retention in care and medication adherence, most of the studies have not focused on older adults, particularly older African American adults, who likely experience additional layers of both stigma and discrimination while navigating systems of care. Sangaramoorthy et al. [23] conducted a systematic review of studies of barriers and facilitators to engagement in care among older African American PLWH, and established that stigma does impact retention in care and medication adherence. However, there is a dearth of research that studies how each strand of stigma (i.e., HIV, race, sex, age) and their subtypes impact different aspects of care engagement among older African American PLWH [23]. As the population of older PLWH continues to increase and racial disparities continue to persist, it is pertinent that we understand how factors like stigma and discrimination impede optimal care among this population.

This study addresses these gaps by exploring the relationships among HIV-related stigma and the different subtypes (i.e., enacted, anticipated, and internalized), experiences of everyday and major discrimination, visit adherence, and medication adherence among older African American PLWH in Ohio. Ohio was an ideal area of focus as three counties (Cuyahoga, Hamilton, and Franklin) were listed as jurisdictions of focus for the Ending the HIV Epidemic initiative as they contributed to over half of new infections in 2019 [45, 46]. Additionally, compared to national estimates of retention in care (57.8%) and viral suppression (65.5%) [3], PLWH in Ohio are less engaged in care [47]. This remains true among older African American PLWH in Ohio, with 38.0% and 58.0% being retained in care and virally suppressed, respectively [47]. This study will help address the factors that are associated with poor engagement among older African American PLWH in Ohio.

Methods

Participants were recruited to participate in an online survey through the Facebook page of the Equitas Health Institute, the education, research, and community engagement division of Equitas Health. Equitas Health is a regional nonprofit community healthcare system serving individuals living with or affected by HIV/AIDS and the lesbian, gay, bisexual, transgender, and queer/questioning (LGBTQ+) community. The healthcare system provides HIV care for a large proportion of PLWH in Ohio with the priority of reducing health disparities in the LGBTQ+and HIV community. The Institute's reach across the HIV community in Ohio goes beyond those seeking services at Equitas Health [48]. Participants were eligible for the study if they were living with HIV, identified as Black or African American, living in Ohio, and 50 years of age and older. Inclusion into the study was determined via self-report. Surveys were offered in English, and were conducted through REDCap, a secure, IRB-approved data collection and storage program [49]. Participants who completed the online survey received a $25 gift card. Due to the pilot nature of this study and limited funds, we initially set our target sample size to be 50 participants. The study was approved by Wright State University's Institutional Review Board.

Study Measures

Demographic characteristics were obtained using self-reported measures. The demographic data included age, time since HIV diagnosis, gender, sexual orientation, highest level of education, employment status, yearly income, and history of injection drug use.

HIV-related stigma—assessed using the Stigma Revised Scale [50]. The Stigma Revised Scale is a 10-item shortened version of the original 40-item Berger HIV Stigma Scale. Item responses were on a 4-point scale and ranged from "strongly disagree" to "strongly agree." Items were summed to create an overall stigma score ranging from 10 to 40; higher scores denote greater experiences of HIV stigma. HIV stigma subscales included personalized stigma (range = 3 to 12), disclosure concerns (range = 2 to 8), negative self-image (range = 3 to 12), and public attitudes regarding HIV (range = 2 to 8). The different subscales were used to describe anticipated HIV stigma (disclosure and public attitudes), enacted HIV stigma (personalized), and internalized HIV stigma (negative self-image).

Everyday discrimination—measured using the everyday discrimination scale [51]. This 9-item scale measures chronic and routine unfair treatment in everyday life. Respondents were asked to list how often any of the experiences (e.g., You are treated with less courtesy than other people are?) happened to them in their day-to-day life. Item responses ranged from "almost every day" to "never." The overall score ranged from 0 to 45 with higher scores denoting more experiences with everyday discrimination. There was a follow-up question that asked respondents to select the main reason for the experiences. The options were ancestry or national origin, gender, race, age, religion, height, weight, other aspect of physical appearance, sexual orientation, and education or income level. Participants were allowed to select more than one reason.

Major discrimination—measured using the major experiences of discrimination scale [52]. This 9-item scale assessed lifetime experiences of discrimination. Respondents were asked if there was ever a time when they were unfairly treated (e.g., fired, not hired for a job, denied a promotion). Respondents could select "yes" or "no." The 9-items were summed to create a score and the overall score ranged from 0 to 9 with higher scores representing more lifetime experiences of discrimination. Similar to the everyday discrimination scale, respondents were asked to select the main reason for the experiences.

Medication adherence—defined using the following question: thinking back over the past 3 months, has there ever been a time where you missed taking all of your antiretrovirals for 4 days or more? Those who answered yes were considered non-adherent.

Visit adherence—participants responded to the following question: in the past 12 months, did you miss any HIV clinic appointments (does not include appointments canceled and rescheduled)? Those who responded yes to this question were considered to be not adherent to visits for that time period.

Statistical Analysis

We produced descriptive statistics for the study population, including means and standard deviations for continuous variables and frequencies and percentages for categorical variables. To examine associations between the main outcomes (i.e., adherence and missed clinic visits) and each of the study variables (i.e., HIV-related stigma, everyday discrimination, and major discrimination), independent two-sample *t*-tests were conducted. Effect sizes were calculated for each relationship using the standardized mean difference. Separate multivariable logistic regression models were used to examine the association between each stigma and discrimination scale and medication and visit adherence. Each model was adjusted for age, time since diagnosis, and sexual orientation. All data were analyzed using SAS version 9.4 (Cary, NC) and *p*-values < 0.05 were regarded as statistically significant. As the study was exploratory in nature, adjustment for multiple comparisons was not conducted. Upon further exploration into the data, one individual who reported to be 50 years of age and older was actually less than 50 years of age. We conducted a sensitivity analysis excluding the individual and no statistically significant difference was made to the results; therefore, they were kept in the study.

Results

A total of 53 participants completed the online survey. The average age was 53.6 ± 2.1 years (range = 27.0 to 58.0) and the average time since diagnosis was 2.9 ± 1.7 years (range = 0 to 7.0). The majority of the sample identified as men (94.3%) and straight/heterosexual (64.2%). The overall HIV-related stigma score was moderately high with a mean of 29.5 ± 2.7. For everyday experiences of discrimination, the mean score was 24.9 ± 8.1; approximately 96% of the participants said the main reason for the discrimination was due to race. For major experiences of discrimination, the mean score was 6.6 ± 2.1 with approximately 89% stating the main reason for the discrimination was due to race (Table 1).

Table 2 presents the HIV-related stigma and experiences of discrimination by medication adherence and missed clinic visits. Almost half (49.1%) of the participants reported that they missed taking all of their antiretrovirals for 4 days or more in the past 3 months and almost a third (31.4%) reported that in the past 12 months, they missed a clinic visit. Overall, those who missed taking their antiretrovirals had slightly higher stigma scores compared to those who did not miss taking their antiretrovirals (mean difference (Δ) = 1.7; effect size (ES) = 0.65; $t = -2.36$; $p = 0.02$). Participants with higher negative self-image scores were more likely to miss their medications compared to those who did not miss taking their medications (Δ = 1.0; ES = 0.71; $t = -2.61$; $p = 0.01$). Respondents with higher levels of major experiences of discrimination were more likely to report that they missed taking their medications compared to those who did not (Δ = 1.7; ES = 0.85; $t = -3.11$; $p = 0.003$). For visit adherence, those who missed a visit within the past 12 months were more likely to experience higher levels of everyday discrimination (Δ = 5.8; ES = 0.76; $t = -3.49$; $p = 0.001$) and major discrimination (Δ = 2.4; ES = 1.35; $t = -5.67$; $p < 0.0001$) compared to those who did not miss a clinic visit in the past 12 months.

Table 3 presents the results from the multiple logistic regression analyses. Each model controlled for age, time since diagnosis, and sexual orientation. Overall HIV-related

Table 1 Characteristics among older African Americans living with HIV in Ohio ($N = 53$)

Characteristics	*n* (%) or mean (SD)	Scale range
Demographics		
Age	53.6 (2.1)	
Time since diagnosis in years	2.9 (1.7)	
Gender—men	50 (94.3)	
Sexual orientation		
Bisexual	6 (11.3)	
Gay	13 (24.5)	
Straight	34 (64.2)	
Education		
High school or less	17 (32.1)	
Technical school/some college	4 (7.6)	
College degree	32 (60.4)	
Yearly income—< $25,000	31 (58.5)	
Employment—full time	17 (32.1)	
History of injection drug use—yes	26 (49.1)	
Stigma and discrimination		
HIV-related stigma	29.5 (2.7)	10–40
Personalized stigma	9.2 (0.9)	3–12
Disclosure	5.8 (0.7)	2–8
Negative self-image	8.5 (1.5)	3–12
Public attitudes	6.1 (1.1)	2–8
Everyday discrimination	24.9 (8.1)	0–45
Major discrimination	6.6 (2.1)	0–9
HIV care outcomes		
Missed taking all of your antiretrovirals for 4 days or more in the past 3 months?—Yes	26 (49.1)	
Missed any HIV clinic visit in the past 12 months?—Yes	16 (31.4)	

Missing values are not included in calculation of percentages

Table 2 Stigma and discrimination by missed medications and clinic visits within 12 months ($N = 53$)

	Medication adherence		Statistical values		
	Yes	No	Mean difference (ES*)	*t*	*p*
	Mean (SD)	Mean (SD)			
Stigma and discrimination					
HIV-related stigma	30.4 (2.5)	28.7 (2.7)	1.7 (0.65)	−2.36	.02
Personalized stigma	9.2 (0.9)	9.1 (1.0)	0.1 (0.12)	−0.46	.65
Disclosure	6.0 (0.7)	5.6 (0.8)	0.4 (0.56)	−2.06	.04
Negative self-image	9.0 (1.0)	8.0 (1.8)	1.0 (0.71)	−2.61	.01
Public attitudes	6.1 (1.0)	6.0 (1.1)	0.1 (0.11)	0.40	.69
Everyday discrimination	27.3 (8.0)	22.5 (7.7)	4.8 (0.62)	−2.24	.03
Major discrimination	7.4 (1.8)	5.7 (2.1)	1.7 (0.85)	−3.11	.003
	Missed clinic visits		Statistical values		
	Yes	No	Mean difference (ES*)	*t*	*p*
	Mean (SD)	Mean (SD)			
Stigma and discrimination					
HIV-related stigma	30.5 (1.9)	29.0 (2.9)	1.5 (0.57)	−1.88	.07
Personalized stigma	9.3 (0.5)	9.1 (1.1)	0.2 (0.14)	−0.62	.54
Disclosure	5.9 (0.8)	5.7 (0.7)	0.2 (0.31)	−1.01	.32
Negative self-image	9.0 (1.5)	8.2 (1.5)	0.8 (0.51)	−1.67	.10
Public attitudes	6.3 (0.7)	5.9 (1.2)	0.4 (0.35)	−1.39	.17
Everyday discrimination	29.2 (2.6)	23.4 (9.0)	5.8 (0.76)	−3.49	.001
Major discrimination	8.3 (1.0)	5.9 (2.1)	2.4 (1.35)	−5.67	<.0001

*ES effect size (mean difference/standard deviation)

stigma (adjusted odds ratio (aOR) = 1.39; 95% confidence interval (CI) = 1.02–1.89), disclosure concerns (aOR = 3.69; 95% CI = 1.25–10.87), and negative self-image (aOR = 2.20; 95% CI = 1.22–10.87) were all associated with an increase in odds of missing their medication in the past 3 months. Major discrimination was associated with missed medications (aOR = 1.70; 95% CI = 1.11–2.60) although everyday experiences of discrimination was not (aOR = 1.09; 95% CI = 0.99–1.20). None of the stigma scales were associated with visit adherence, although there was a threefold increase in odds for disclosure concerns (aOR = 3.13; 95% CI = 0.93–10.53). For every one unit increase in experiences of major discrimination, there was a threefold increase in the odds of missing a clinic visit (aOR = 3.24; 95% CI = 1.38–7.64).

Table 3 Adjusted odds ratios for medication adherence[a] and missed clinic visits among older African Americans living with HIV in Ohio ($N = 51$)

	Medication adherence		Missed clinic visits*	
	aOR	95% CI	aOR	95% CI
HIV-related stigma[a]	1.39	1.02–1.89	1.31	0.95–1.83
Personalized stigma[a]	0.87	0.43–1.75	0.81	0.37–1.80
Disclosure[a]	3.69	1.25–10.87	3.13	0.93–10.53
Negative self-image[a]	2.20	1.22–3.98	1.68	0.97–2.90
Public attitude[a]	0.99	0.55–1.77	1.15	0.58–2.29
Everyday discrimination[a]	1.09	0.99–1.20	1.13	0.98–1.30
Major discrimination[a]	1.70	1.11–2.60	3.24	1.38–7.64

[a] The logistic regression modeled the probability of non-adherence

aOR adjusted odds ratio

CI confidence interval

Note: each model controlled for age, time since diagnosis, and sexual orientation

*Two individuals had missing values and were removed from the model

Discussion

The purpose of this study was to explore the associations among HIV-related stigma, experiences of everyday and major discrimination, visit adherence, and medication adherence among older African Americans living with HIV in Ohio. The participants in this study experienced moderately high levels of HIV-related stigma, as well as everyday and major forms of discrimination, with race articulated as the most identified source of discrimination. Those with higher levels of overall HIV-related stigma, anticipated stigma (disclosure concerns), internalized stigma (negative self-image), and major discrimination were at greater odds of not adhering to their medication. Additionally, those with higher levels of experience with major discrimination were at higher odds of missing at least one clinic visit within a 12-month period.

Our findings provide additional evidence to a small but growing body of literature that demonstrates that stigma and discrimination impact engagement in HIV care. We build on this literature by focusing exclusively on the experiences of older African American PLWH, who are positioned to experience stigma and discrimination from a complex constellation of factors, including but not limited to HIV status, race, gender, sexual orientation, and age. Furthermore, through logistic regression, we are able to tease out how particular strands of intersecting stigma and forms of discrimination impact specific outcomes, such as medication adherence or HIV care visit attendance. Among our sample, we found that higher levels of internalized and anticipated HIV-related stigma were associated with higher odds of poor medication adherence. Other researchers have suggested that higher experiences of internalized and anticipated stigma have a negative effect on medication adherence [26, 27, 53, 54]. As some PLWH may not have disclosed their status to others, experiences of internalized and anticipated stigma may lead to social isolation and low social support, which then may negatively impact engagement in care [6]. None of the stigma variables were significantly associated with visit adherence. However, there was a 68% increase in odds of missing a clinic visit for each unit increase in negative self-image (internalized HIV stigma) and a threefold increase in odds of missing a clinic visit for each unit increase in disclosure concerns (anticipated HIV stigma). Other researchers have shown associations between internalized stigma and visit adherence. Among a sample of PLWH in Alabama ($N = 196$), Rice et al. [26] showed a decrease in visit adherence with increasing levels of internalized stigma. In a much larger study ($N = 6{,}448$), Christopoulos et al. [53] showed a 10% increase in odds of missed clinic visits for each unit increase in an internalized stigma score. Although not statistically significant, the magnitude of the effects in our study was much higher than those observed in previous studies. Our study's small sample size may explain the non-significant associations.

Experiences of everyday discrimination were not associated with medication adherence or missed clinic visits; however, major experiences of discrimination were associated with both medication and visit adherence. This may not be surprising as acute, everyday experiences of discrimination at that moment in time may have a short-term impact on engagement and health outcomes while chronic, severe exposure can lead to poor engagement and negative health outcomes over time. Furthermore, participants overwhelmingly indicated that race was the primary source of experiences of discrimination, and it is likely that experiences of racial discrimination predated their HIV diagnosis, shaping attitudes and expectations of the healthcare system from an early age. Exposure to major forms of discrimination can have a major impact on trust and certain health behaviors. Researchers have shown that exposure to discrimination leads to medical mistrust which then leads to poor engagement in HIV care [36–38, 43]. In a study among 57 PLWH, Boarts et al. [37] showed a negative relationship between past-year racial discrimination and HIV treatment adherence as well as lifetime racial discrimination, which supports our findings. We were not able to explore the pathways through which discrimination affects medication and visit adherence, but future studies should look at this among older African Americans living with HIV.

Limitations

This study has several limitations. First, this was a pilot study and the objective was to explore the relationships among discrimination, stigma, medication adherence, and missed clinic visits. Due to our sample size, we did not adjust for multiple comparisons and the study was not adequately powered to detect all effects. Second, our sample may not be generalizable to the overall population of older African American PLWH in Ohio. Participants were recruited through an AIDS service organization's social media page and so our sample consisted of those with access to the organization's social media page and/or individuals comfortable using digital technologies and social media. It is likely that we did not reach the entire older African American population living with HIV in Ohio, and perhaps more importantly older individuals who did not have a college education, and may be less comfortable with the use of technologies or did not feel comfortable interacting with HIV-related service organizations on social media due to stigmas surrounding both HIV status and homosexuality in African American communities [55].

Our study sample may not reflect our true population of interest. Our participants were comparatively young and were recently diagnosed with HIV. We may be studying the impact of stigma and discrimination among those recently diagnosed as opposed to those who were diagnosed at an earlier age. The impact of stigma and discrimination on these two populations may be different. Additionally, our sample consisted of mostly men. The effect of stigma and discrimination on engagement in HIV care may be different for older African American men compared to older African American women living with HIV and could have had an impact on our findings had we had a larger sample of women. We limited our sample to only those who read and understand English, so we may have excluded a number of participants that identify as black and living with HIV, but are less comfortable communicating in English. Furthermore, we did not anticipate a relatively high percentage of injection drug users in the sample, and did not include questions that pertained to an additional and potentially interesting strand of intersecting stigma and discrimination that emerges from a background in drug use [14]. Future iterations of this study will include questions relating to stigma and discrimination, as well as navigation of care related to substance use and particularly injection drug use. Another limitation is that this study was a cross-sectional study, so causation cannot be implied. We relied on self-reported data to assess the relationship among stigma, discrimination, and engagement. There's a possibility that the results could be impacted by recall bias and/or social desirability bias. Additionally, socio-demographics were also self-reported, and due to the pilot nature of this study, we did not include validation measures in our recruitment procedures. Future, more developed stages of this project will include more rigorous accountability procedures to ensure that the sample size reflects the intended demographic. Finally, our results should be interpreted with caution as we may have uncontrolled confounding in our study.

Conclusion

Our findings suggest that among older African American PLWH, overall HIV-related stigma, internalized stigma, anticipated stigma, and major experiences of discrimination were all associated with medication adherence while just major experiences of discrimination were associated with visit adherence. As the population of older PLWH continues to increase and the racial disparities remain, it is important that more studies focus on this population to understand how stigma and discrimination work to impede optimal engagement in care.

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Declarations

Ethics Approval The study was approved by Wright State University's Institutional Review Board.

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

Consent for Publication N/A

Competing Interests The authors declare no competing interests.

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