### **ORIGINAL PAPER**



# HIV Information Avoidance, HIV Stigma, and Medical Mistrust among Black Sexual Minority Men in the Southern United States: Associations with HIV Testing

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#### **Abstract**

Uptake of HIV testing is a critical step in the HIV prevention and treatment care cascade. Barriers to HIV testing, however, remain and innovative research in this area is warranted to improve uptake of testing. As such, we investigated the role of HIV information avoidance - a novel construct potentially related to HIV testing. We analyzed this construct in relation to other factors known to impact HIV testing, namely HIV stigma and medical mistrust. Multiple linear regression analyses indicated that HIV information avoidance was negatively associated with HIV testing, while medical mistrust was positively associated with HIV testing. HIV testing stigma was not associated with HIV testing. This work contributes to the developing literature on HIV information avoidance and its relationships with HIV stigma and HIV testing uptake. Further, these findings can inform HIV testing interventions which often do not focus on HIV information avoidance. Future research on the mechanisms of information avoidance that are amenable to intervention, and the temporal ordering of the relationship between information avoidance and HIV testing is warranted.

Keywords Health Information Avoidance · HIV Testing · HIV Stigma · Medical Mistrust · Black Sexual Minority men

Accessing HIV testing and HIV prevention tools is critical for slowing the HIV epidemic. Challenges to accessing this care, however, continue and the need for research to understand barriers remains [1, 2]. One consideration for better understanding these barriers is the degree to which individuals may purposefully avoid health-related information or behavioral health practices such as HIV testing, known as information avoidance [3, 4]. Information avoidance specific to HIV can be particularly detrimental because it may

lead to a lack of diagnosis and delay in treatment [3]. Understanding the relationship between HIV information avoidance and HIV testing behaviors may provide novel insight into areas of opportunity for intervention work. Research in this area is limited and it is unknown the extent to which HIV information avoidance is related to HIV testing frequency, in particular, when controlling for known factors related to HIV testing such as HIV stigma and medical mistrust.

Health information avoidance may occur for a variety of reasons: to maintain hope about one's life course, to manage misinformation, or to avoid potential psychological threats related to health concerns [5, 6]. The avoidance of HIV-related health information suggests that some individuals believe HIV to be a disease that should not be discussed, should be avoided, or be willfully ignored. HIV stigma is a related, but distinct concept. Measures pertaining to HIV stigma are often restricted to specific aspects of stigma (e.g., anticipated, internalized, enacted) rather than assessing multiple and differing constructs that are representative of stigma, such as HIV information avoidance. One such assessment is HIV testing stigma, in particular, anticipated

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stigma in relation to HIV testing (e.g., not wanting to be seen at HIV testing site) [1]. Although HIV testing stigma has clear implications for understanding HIV testing uptake, other stigma-related constructs such as HIV information avoidance may be more strongly associated with HIV testing than HIV testing stigma.

Medical mistrust may also be associated with health information avoidance and HIV prevention and treatment services [7]. Medical mistrust—a wariness and/or suspicion of healthcare systems, providers, or treatments—is often rooted in the systemic marginalization of minoritized populations [8]. Mistrust of medicine and the healthcare system may be adaptive and justifiable in the face of discrimination or prejudice that many racial/ethnic diverse groups experience [7, 9]. However, ongoing mistrust may also discourage engagement with healthcare systems and practitioners and by extension delay diagnoses or treatment of health conditions. It is, therefore, important to consider the impact of medical mistrust while investigating the relationship between HIV information avoidance and HIV testing.

## **Current Study**

To understand the unique impact of HIV information avoidance on HIV testing, we assessed the relationships between HIV information avoidance, HIV testing stigma, medical mistrust, and HIV testing frequency [7, 10–12]. We sought to understand the relative contribution of variance in the association between our variables of interest and HIV testing frequency via multiple linear regression analysis. The current study is exploratory in nature, yet given prior research on health information avoidance, [3, 13] we expected that as HIV information avoidance increased HIV testing frequency would decrease. The extent to which this relationship would hold in the context of known variables (e.g., HIV testing stigma and medical mistrust) impactful on HIV testing frequency is unknown and the primary focus in the current manuscript.

### Method

## **Procedure and Participants**

Participants were recruited for the current study using online social media and participant referral. Recruitment was targeted to the Atlanta, GA metro area. All participants were screened eligible if they reported African American/Black identity, anal sex with a man in the past year, assigned male sex at birth, HIV negative status, and being at least 18 years of age or older. All participants provided written informed

consent for all study procedures and this study received Institutional Review Board approval. Study survey activities were completed using Audio Computer Assisted Self-Interviewing (ACASI) software. Data were collected as part of the baseline survey of a larger randomized controlled trial conducted between 2017 and 2019.

#### Measures

### **Demographic Characteristics**

Participants were asked a series of questions to assess demographic and background characteristics such as age (in years), income, employment status, ethnicity, relationship status, and access to a regular doctor. Income was assessed on a 0- (\$0 - \$10,000) to 7 (\$61,000 or higher) scale.

#### **HIV Testing and Sex Partners**

Participants received a single-item measure that asked about their frequency of HIV testing, specifically how many times they have been tested for HIV in their lifetime. Participants responded on a 0- (0 times) to 4 (7 or more times) scale. In addition, participants were asked about recent sex history, specifically, how many male sexual partners they had had in the past 3 months.

#### **HIV Information Avoidance**

Participants responded to an 8-item measure of HIV information avoidance related to HIV testing adapted from similar measures of health information avoidance [4, 6, 14]. Items were on a 1 (Strongly Disagree) to 6 (Strongly Agree) response set, examples include: "I would rather not know my HIV status" and "When it comes to knowing my HIV status, ignorance is bliss." Higher average scores indicated greater HIV information avoidance. The HIV information avoidance measure showed acceptable reliability in our sample,  $\alpha = 0.75$ .

## **HIV Testing Stigma**

Participants responded to a 14-item measure of HIV testing stigma to assess the degree of anticipated stigma they experience surrounding HIV testing (adapted from Boshamer and Bruce) [15]. Items were on a 1 (Strongly Disagree) to 6 (Strongly Agree) response set, example items included: "I am afraid that if I were to be tested for HIV, my name would go into public records" and "People would assume I have HIV if I decided to get tested." Higher average scores indicated greater levels of anticipated HIV testing stigma. The



HIV testing stigma measure showed acceptable reliability in our sample,  $\alpha = 0.78$ .

#### **Medical Mistrust**

Participants responded to a 4-item measure assessing the degree to which participants reported mistrust of healthcare workers (adapted from Thompson and colleagues) [16]. Items were on a 1 (Strongly Disagree) to 6 (Strongly Agree) response set, example items included: "People should be suspicious of information from doctors and healthcare workers" and "People should not confide in doctors and healthcare workers because it will be used against them." Higher average scores indicated greater mistrust. This measure showed acceptable reliability in our sample,  $\alpha = 0.72$ .

## **Data Analytic Plan**

We conducted descriptive analyses followed by bivariate correlations to assess potential associations among our variables of interest. Following these analyses, we performed multiple linear regression by regressing HIV testing frequency onto HIV information avoidance, HIV testing stigma, and medical mistrust. We also included age (in

**Table 1** Sociodemographic characteristics among Black sexual minority men residing in and around the Atlanta, GA metro area (*N*=483)

Demographic characteristic	n	%	
Education			
≤ Some college	326	67.5	
> Some college	157	32.5	
Sexual orientation			
Bisexual	127	26.3	
Gay	256	53.0	
Heterosexual	5	1.0	
Same-gender loving	95	19.7	
Income			
≤ \$30,000	317	65.8	
> \$30,000	165	34.2	
Employment			
Working full-time	246	50.9	
Working part-time	113	23.4	
Student	76	15.7	
Unemployed	70	14.5	
Disability	24	5.0	
Other	61	12.6	
Insurance			
Private insurance	217	44.9	
Public insurance	74	9.5	
No coverage	180	37.3	
Other	40	8.3	
Regular doctor (yes)	274	56.8	
PrEP use (no)	463	96.1	
Relationship status (not married)	467	96.7	
Age (in years)	M = 31.53	SD = 10.04	

years), income, educational attainment, access to a regular doctor, and number of male sexual partners in the past 3 months as additional covariates in the model.

Inspection of the data revealed moderate skew and several outliers ( $n \le 5$  for all variables) in reports of HIV information avoidance. Outliers were considered responses that were more than three times the interquartile range from the average score (i.e., extreme outliers using Tukey's method). However, after removing outliers and conducting a log transformation of skewed variables, findings remained the same. Thus, original analyses are reported below. The final data analytic sample for this study was 483 Black sexual minority men (BSMM)—nine participants were dropped from analyses because they did not identify as male (i.e., 8 transgender women and 1 who reported 'other' as their gender identity). Though taking PrEP at study completion could potentially be related to study outcomes, n = 20 participants who were currently taking PrEP were included in the analytical sample because correlation analyses suggested that current PrEP use was not associated with our variables of interest. All analyses were conducted using IBM SPSS v27.

## **Results**

Sample demographic characteristics are reported in Table 1. On average, participants were 31.53 years old (SD = 10.04). Approximately half of the sample reported working fultime (n = 246; 50.9%) or part-time (n = 113; 23.4%). Twothirds of participants reported both an annual income of \$30,000 or less (n = 317; 65.8%) and some college or less (n = 326; 67.5%). Slightly less than half of the participants reported having no health coverage at some point during the last two years (n = 219; 45.4%), with slightly more than half of the participants reporting that they had no regular doctor or healthcare provider (n = 274; 56.8%). The majority of participants identified as gay (n = 256; 53.0%), followed by bisexual (n = 127; 26.3%), and same gender loving (n = 95; 19.7%).

Participants reported low levels of HIV information avoidance (M=1.52, SD=0.75), and reported between "strongly disagree" and "somewhat disagree" on assessments of HIV information avoidance. Further, participants reported low average levels of HIV testing stigma (M=1.52, SD=0.60), and reported between "somewhat disagree" and "strongly disagree" on endorsement of messages indicative of HIV testing stigma. Participant reports of medical mistrust were also moderate (M=2.73, SD=1.01) on average. Additionally, participants on average reported having been tested for HIV about 3–4 times (M=2.95, SD=1.22).

We found statistically significant associations between HIV testing and several variables of interest. Specifically,



bivariate correlations demonstrated that frequency of HIV testing was significantly negatively associated with HIV information avoidance, r(483) = -0.22, p < .001, and HIV testing stigma, r(483) = -0.13, p < .01. Individuals who reported having been tested for HIV reported lower levels of HIV information avoidance and HIV testing stigma. However, participant reports of medical mistrust, r(483) = 0.06, p > .05, was not significantly associated with HIV testing frequency (see Table 2).

Our variables of interest accounted for a significant portion of the variance in HIV testing frequency, F(8, 468) = 11.97, p < .001,  $R^2 = 0.17$ . Further, HIV information avoidance, B = -0.27, t(468) = -3.45, p < .001, and medical mistrust, B = 0.10, t(468) = 1.91, p < .05, were significantly associated with HIV testing frequency. That is, greater levels of HIV information avoidance were associated with a lower frequency of HIV testing; and greater levels of medical mistrust were associated with a greater frequency of HIV testing. However, HIV testing stigma, B = -0.13, t(468) = -1.25, p > .05, was significantly associated with HIV testing frequency (see Table 3).

## **Discussion**

Participants' avoidance of health-related information—particularly related to HIV testing outcomes—is concerning and an important yet overlooked area for intervention development. Our findings contribute to a better understanding of health information avoidance and confirm the importance of HIV information avoidance among BSMM. We found that HIV information avoidance was strongly associated with HIV testing frequency beyond related constructs, such as assessments of HIV testing stigma or medical mistrust. These findings suggest that researchers should consider expanding the ways in which stigma is measured in HIV research as well as tailoring interventions to pointedly address HIV information avoidance.

Our multiple linear regression analyses revealed that HIV information avoidance and medical mistrust were associated with HIV testing frequency while HIV testing stigma was not, among BSMM. The parameter estimate of HIV information avoidance was also twice that of medical mistrust. While higher levels of medial mistrust may be associated with more frequent HIV testing, the degree to which HIV information avoidance reduced HIV testing suggests a particular need for interventions targeting health information avoidance. These findings also indicate a greater need to investigate the relationship between HIV information avoidance, medical mistrust, and HIV testing stigma as these constructs pertain to behavioral health practices.

 $\infty$ 0.49\*\*\* 0.23\*\*\* 0.16\*\*\* -0.11\*0.02 -0.070.07 0.04 -0.003-0.10\*-0.02-0.04able 2 Means, standard deviations, and Pearson's correlations among variables of interest -0.11\* -0.10\*0.29\*\*\* 0.26\*\*\* 0.17\*\*\* 0.07 .52(0.75).52(0.60)2.73 (1.01) 3.14 (5.67) 5. Number of male sexual partners 2. HIV information avoidance 3. HIV testing stigma 4. Medical mistrust 8. Regular doctor .HIV testing Education 7. Income

*Vote.* Degrees of freedom for correlations with HIV testing is 483 and 479 for all other correlations  $^{b}$   $^{c}$ .05,  $^{**}$   $^{p}$   $^{c}$ .01,  $^{***}$   $^{p}$   $^{c}$ .001



Table 3 Bivariate and multivariable linear regression results of associations with HIV testing frequency

Variable	Bivariate <sup>a</sup>			Multivariable <sup>b</sup>		
	B (SE)	β	95% CI	B (SE)	β	95% CI
Intercept		,		1.91 (0.26)	***	[1.39, 2.43]
HIV information avoidance	-0.35 (0.07)	-0.22***	[-0.49, -0.21]	-0.27 (0.08)	-0.16***	[-0.42, -0.11]
HIV testing stigma	-0.27 (0.09)	-13**	[-0.45, -0.09]	-0.13 (0.10)	-0.06	[-0.32, 0.07]
Medical mistrust	0.07 (0.06)	0.06	[-0.04, 0.18]	0.10 (0.05)	0.09*	[-0.003, 0.21]
Number of male sexual partners	0.02 (0.01)	0.07	[-0.004, 0.03]	0.02 (0.01)	0.09*	[0.002, 0.04]
Age	0.04 (0.01)	0.29***	[0.03, 0.05]	0.03 (0.01)	0.23***	[0.02, 0.04]
Income	0.17 (0.03)	0.26***	[0.12, 0.23]	0.09 (0.03)	0.14**	[0.03, 0.16]
Regular doctor	0.28 (0.11)	0.11*	[0.06, 0.50]	0.08 (0.11)	0.03	[-0.13, 0.29]
Education	0.18 (0.05)	0.17***	[0.09, 0.27]	0.05 (0.05)	0.05	[-0.05, 0.15]
R [2]				0.17		
F(8, 468)				11.97***		

Note. <sup>a</sup>All values listed under the bivariate column represents a linear regression analysis that includes only the variable noted. <sup>b</sup>All values listed under the multivariable column includes all variables in the model. B=unstandardized coefficients, SE=standard error,  $\beta$ =standardized coefficients, CI=95% confidence intervals

Although we expected HIV information avoidance to be associated with HIV testing frequency (i.e., greater avoidance was associated with lower testing rates), it was unknown the extent to which HIV testing stigma would be related to HIV testing while investigating information avoidance. One possibility is that HIV information avoidance is similar to HIV testing stigma in contributing overlapping variance but also contributes its own unique variance to HIV testing not currently assessed in the broader HIV stigma literature. If an individual intentionally avoids HIV-related information entirely, then experiences specific to HIV testing stigma may not be prevalent in that individual's life. There is some research to suggest this scenario in other areas of health information avoidance research. For instance, an individual must be persuaded to engage with cancer-related information prior to any considerations of testing [13, 17, 18]. Thus, health information avoidance may be more strongly associated with behavioral health practices than the information or stigma-related behavior, but less work has found this relationship in the context of HIV research. However, as the absence of statistically significant results does not necessarily indicate that there is no relationship between information avoidance, testing stigma, and HIV testing, this interpretation should be taken with caution. Future research should investigate the temporal relationship between HIV stigma, HIV information avoidance, and HIV testing stigma and the potential causal mechanism associated with HIV testing.

When including all variables in the multiple linear regression analyses, we also found that medical mistrust was associated with HIV testing frequency. Specifically, medical mistrust was positively associated with HIV testing frequency such that as medical mistrust increased, HIV testing frequency also increased. One explanation for this findings is that greater medical mistrust could also counterintuitively be an indicator of greater healthcare engagement. An individual with greater healthcare engagement may report more negative experiences because they interact with the healthcare system more frequently, regardless of stigmatization. The need to confirm results due to a mistrust of the medical system has some support in previous research. For instance, research has found that high levels of HIV conspiracy beliefs was associated with a significantly greater likelihood of being tested for HIV [7]. Other qualitative research has also found that individuals may weigh the trade-offs of medical mistrust and self-care behaviors, with many still choosing to engage in HIV testing despite significant mistrust of the healthcare system [19, 20].

Interestingly, our bivariate correlation analyses did not reflect the findings from the multiple linear regression analyses. We found that HIV testing stigma was associated with HIV testing frequency while medical mistrust was not associated with HIV testing frequency, but the relation between HIV information avoidance and HIV testing was consistent throughout our analyses. One explanation for these findings may be that medical mistrust is dependent on other related factors. The combined relative contributions of variance by medical mistrust and HIV information avoidance may entirely overlap with the relative contribution of HIV testing stigma on HIV testing. This explanation also applies to medical mistrust such that when investigated alone in a



bivariate analysis, medical mistrust does not provide a more comprehensive understanding of HIV testing. However, when other variables are controlled for, medical mistrust is a significant factor in its association with HIV testing. This may also indicate that assessment of HIV information avoidance and medical mistrust together heavily overlaps with HIV testing stigma. Given the inconsistencies in these analyses, further research is needed to comprehensively understand these relationships.

Our findings are also notable contributions to research focused on health information avoidance more generally. There is a dearth of research on HIV information avoidance [21] —most of the research on health information avoidance does not pointedly focus on HIV. Thus, our work represents a step forward in understanding how HIV information avoidance functions in the context of HIV stigma and testing. As it pertains to HIV information avoidance, research suggests that health information avoidance is fluid and when individuals are asked to reflect on why they avoid certain information, they rely on pre-existing implicit attitudes toward a given disease (i.e., automatic versus controlled processes) [17]. If a disease is especially stigmatized at the intersection of race and sexual orientation, such as HIV, negative attitudes (i.e., implicit bias) may discourage information seeking. This is especially relevant as current work also finds that attitudes within one's own community (i.e., surrounding social network) are associated with information avoidance [22].

In terms of limitations, individuals who self-select into a HIV-related research study may show lower levels of HIV information avoidance relative to other BSMM given their interest in being a part of the study. Further, the average age (i.e., 30 years old) and general range of ages in our sample was also slightly higher than individuals who may be at a higher risk for contracting HIV, specifically those in emerging adulthood (approximately 18-24 years old) [23]. Further, the majority of our sample consisted of BSMM who did not use PrEP, therefore, a sample comprised of PrEP users may show a different relation between HIV information avoidance and HIV testing outcomes. Our measure of HIV information avoidance was also adapted from Howell and Shepperd (2016) and therefore, has not yet been validated [14]. This measure also demonstrated a 'floor effect' (e.g., the distribution of the data were skewed such that participants reported low information avoidance). Our interpretation of the findings related to medical mistrust is also limited, as assessment of the type of testing center a participant went to was outside the scope of these data. Future research should rectify this limitation and investigate the role of type of testing center in relation to information avoidance, medical mistrust, and stigma. Finally, we assessed lifetime HIV testing frequency, but future research should

consider other HIV-related health outcomes or assessments of HIV testing such as time in between HIV tests.

### **Conclusion**

As research on HIV stigma continues to develop, it is important to consider constructs that overlap with HIV stigma or health behaviors. To understand these related constructs, we investigated how HIV information avoidance relates to HIV testing outcomes. We found that HIV information avoidance is associated with HIV testing and that the effect of HIV information avoidance appears to be stronger than that of common assessments of HIV stigma (e.g., anticipated stigma; experiences of discrimination). Future research should continue to investigate the impact of HIV information avoidance on the efficacy of HIV testing interventions. Our findings represent an opportunity to advance our understanding of stigma and to tailor interventions that best serve the needs of BSMM.

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Data Availability Data are available upon request.

Code Availability Code availability is not applicable.

#### **Declarations**

**Conflict of interest** The authors declare that there are no conflicts of interests (or competing interests).

Ethics approval and consent to participate This study was approved by the University of Connecticut Institutional Review Board. All participants represented in this study consented to participate and to have their individual data used in this manuscript.

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