

# Examining the Relationships Between Experienced and Anticipated Stigma in Health Care Settings, Patient–Provider Race Concordance, and Trust in Providers Among Women Living with HIV

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## Abstract

Stigma in health care settings can have negative consequences on women living with HIV, such as increasing the likelihood of missed visits and reducing trust in their clinical providers. Informed by prior stigma research and considering knowledge gaps related to the effect of patient–provider race concordance, we conducted this study to assess if patient–provider race concordance moderates the expected association between HIV-related stigma in health care settings and patients’ trust in their providers. Moderation analyses were conducted using Women’s Interagency HIV Study data ( $N=931$ ). We found significant main effects for patient–provider race concordance. Higher experienced stigma was associated with lower trust in providers in all patient–provider race combinations [White–White:  $B=-0.89$ , standard error (SE)=0.14,  $p=0.000$ , 95% confidence interval, CI (-1.161 to -0.624); Black patient–White provider:  $B=-0.19$ , SE=0.06,  $p=0.003$ , 95% CI (-0.309 to -0.062); and Black–Black:  $B=-0.30$ , SE=0.14,  $p=0.037$ , 95% CI (-0.575 to -0.017)]. Higher *anticipated* stigma was also associated with lower trust in providers [White–White:  $B=-0.42$ , SE=0.07,  $p=0.000$ , 95% CI (-0.552 to -0.289); Black patient–White provider:  $B=-0.17$ , SE=0.03,  $p=0.000$ , 95% CI (-0.232 to -0.106); and Black–Black:  $B=-0.18$ , SE=0.06,  $p=0.002$ , 95% CI (-0.293 to -0.066)]. Significant interaction effects indicated that the negative associations between experienced and anticipated HIV-related stigma and trust in providers were stronger for the White–White combination compared with the others. Thus, we found that

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significant relationships between HIV-related experienced and anticipated stigma in health care settings and trust in providers exist and that these associations vary across different patient–provider race combinations. Given that reduced trust in providers is associated with antiretroviral medication nonadherence and higher rates of missed clinical visits, interventions to address HIV-related stigma in health care settings may improve continuum of care outcomes.

**Keywords:** HIV, health equity, race, women living with HIV, moderation analysis, WIHS

## Introduction

**E**LIMINATING STIGMA in health care settings is a high-priority public health goal.<sup>1–3</sup> Prior studies suggest that stigma is associated with negative health outcomes across the HIV continuum of care, from increased rates of missed HIV care visits to lower rates of viral load suppression.<sup>4–6</sup> While some research reports on the experiences of patients from various racial backgrounds, few studies collect health providers' race and assess the effects of patient–provider racial concordance on patients' experienced and anticipated stigma in health care settings or on how these stigma dimensions and patient–provider race concordance may be related to patients' trust in their HIV health care providers. To the best of our knowledge, no studies have examined the effects of patient–provider race concordance on the relationship between HIV-related anticipated and experienced stigma and patients' trust in providers among women living with HIV (WLHIV). Thus, we aim to test the potential moderation effect of patient–provider race concordance on the hypothesized association between HIV-related stigma in a health care setting and trust in HIV providers.

### *HIV-related stigma*

Stigma is based on an attribute that is deeply discrediting, which devalues the bearer from those who are unmarked by the stigmatizing attribute.<sup>7</sup> Discriminatory treatment occurs as a consequence of stigma; it is experienced when entities holding social power treat those with stigmatized identities or devalued characteristics differently.<sup>8</sup> Link and Phelan (2006) described the stigmatization process: people distinguish and label human differences; resulting dominant societal views label persons with undesirable attributes; labeling leads to a separation between “us” and “them”; and persons labeled with undesirable attributes suffer loss of status, rejection, and other discriminatory treatment; and this process is enabled and perpetuated by those who exercise authority and influence,<sup>9</sup> such as health care providers.

HIV-related stigma is harmful, resulting in negative health consequences such as increased rates of depression, feelings of low self-worth, lower rates of antiretroviral medication adherence, and lower rates of viral suppression;<sup>10–13</sup> WLHIV also experience intersectional stigma due to other undervalued or diminished aspects of their identities, such as being a woman, being poor, or being a racial or ethnic minority.<sup>14</sup>

### *Stigma dimensions*

Earnshaw and Chaudoir's HIV Stigma Framework (HSF) provides a fitting heuristic model for our study.<sup>15,16</sup> The HSF suggests that there are three primary stigma dimensions that affect the well-being of people living with HIV (PLHIV): enacted stigma, anticipated stigma, and internalized stigma.

Enacted or experienced stigma and discrimination refer to the differential treatment from others.<sup>15,16</sup> When stigma is enacted against PLHIV, they may feel powerless and demeaned,<sup>17</sup> causing them to avoid future interaction with the stigmatizing person or institution.<sup>18</sup> Anticipated stigma is the expectation of enacted stigma. If someone is living with HIV and she expects to be treated differently than others because of her HIV status, she is anticipating stigma. Anticipated stigma has been shown to be associated with delays in seeking HIV prevention services and increases in antiretroviral medication nonadherence.<sup>19,20</sup> Internalized stigma is the personal acceptance of negative characterization. In the context of health care settings—environments that should be propatient and free of discrimination—researchers can measure experiences of enacted or anticipated HIV-related stigma by surveying patients to understand the scope of these issues as well as the potential impact on patient health, quality of care, and trust in providers.

### *Patient–provider concordance in race*

Examination of the association between racial concordance and patient health outcomes is occurring across multiple disciplines. A meta-analysis cataloging 27 studies of patient–provider racial concordance across a range of medical conditions produced mixed results, with a third of the studies finding that patient–provider race concordance is associated with positive health outcomes, a third offering mixed results, and a third offering no definitive assessment on impact.<sup>21</sup> In contrast, a study across 30 community health centers in the New York area found that communication and clinical adherence relationships were modified when there was patient and provider race discordance, but that there was no significant association between communication and adherence when there was provider and patient race concordance.<sup>22</sup> These and other studies suggest that while racial concordance may be impactful on health outcomes,<sup>21–24</sup> other variables also play a role in the delivery of high-quality care and health outcomes.

### *Trust in providers and stigma in health care settings*

Racial minorities experience racism, discrimination, and implicit bias across multiple settings: professional environments, community neighborhoods, and clinical settings; these stigmatizing experiences have serious implications for well-being.<sup>10,25</sup> Research with racial and ethnic minorities living with HIV has shown that enacted HIV-related stigma in health care settings is associated with increased depressive symptoms, health care avoidance, and decreased trust in one's physician.<sup>26</sup> Research on patients' perceptions of provider trustworthiness spans across multiple health conditions, affecting an array of diverse populations. For example, an HIV pre-exposure prophylaxis (PrEP) study found a positive

association between patients' trust in their providers and willingness to accept PrEP.<sup>27</sup> Another study offered evidence suggesting a strong relationship between trust in providers and medication adherence among adults living with diabetes,<sup>28</sup> and a study conducted with women experiencing breast cancer found that a lack of trust in providers was associated with a greater likelihood of reporting race-related discrimination in health care settings.<sup>29</sup> What appears to be a consistent trend is that patients of color experience stigma in clinical settings and that when they encounter this stigma, their trust in providers is reduced, leading to negative health consequences.

## Methods

### *Data, participants, and procedures*

The Women's Interagency HIV Study (WIHS, established in 1993)<sup>30</sup> is a national, prospective cohort study designed to longitudinally examine behavioral and clinical outcomes among WLHIV and women at risk for HIV in the United States; the WIHS was expanded to include sites in the southern United States in 2013.<sup>31</sup> WIHS protocols and procedures are described elsewhere.<sup>30</sup> In this study, WLHIV from nine WIHS sites ( $N=931$ ) located in Brooklyn; the Bronx; Washington, D.C.; Chicago; Atlanta; Birmingham; Jackson; Miami; and Chapel Hill were included. Ethical approvals were obtained from Institutional Review Boards at all recruitment sites. Participants provided written informed consent.

### *Measures*

**Patient-provider race concordance.** When describing their primary HIV care provider, over 75% ( $n=711$ , 76.4%) stated that their primary HIV provider was White and 23.6% reported their primary HIV provider was African American or Black (including Afro-Caribbean or of African descent, henceforth referred to as Black). We created a new categorical variable to represent three race combinations based on patient-provider race: White-White ( $n=146$ ), Black patient-White provider ( $n=565$ ), and Black-Black ( $n=220$ ). We excluded the White patient-Black provider combination and combined Hispanic and non-Hispanic due to small subsample sizes.

**Experienced HIV-related stigma in a health care setting.** Experienced HIV-related stigma in any health care setting was assessed with six items adapted from the enacted stigma section of a tool developed for measuring HIV-related stigma among health facility staff.<sup>32</sup> The items (e.g., "healthcare workers were unwilling to care for you because you are living with HIV") are rated on a 5-point Likert scale, ranging from 1=never to 5=almost always. In this study, Cronbach's coefficient was  $\alpha=0.75$ .

**Anticipated HIV-related stigma in a health care setting.** Anticipated stigma in any health care setting was assessed with three items, namely health care workers will not listen to my concerns; health care workers will avoid touching me; and health care workers will treat me with less respect. Items were from the HSF scale.<sup>33</sup> Responses were on a 5-point scale, ranging from 1=very unlikely to 5=very likely. In our data, Cronbach's coefficient was  $\alpha=0.89$ .

**Race- and ethnicity-related stigma or implicit racial bias in a health care setting.** Race- and ethnicity-related stigma or implicit racial bias in any health care setting was assessed with two items from the discrimination subscale of the Interpersonal Processes of Care Survey,<sup>34</sup> specifically "In the past 12 months, how often did healthcare workers pay less attention to you because of your race or ethnicity?" and "In the past 12 months, how often did you feel discriminated against by healthcare workers because of your race or ethnicity?" Responses were on a 5-point scale, ranging from 1=never to 5=almost always. In our data, Cronbach's coefficient was  $\alpha=0.98$ .

**Trust in HIV providers.** Trust in one's HIV provider was assessed with the validated, eight-item, Safran Physician Trust Subscale of the Primary Care Assessment Survey (PCAS).<sup>35</sup> A sample item is "You completely trust your HIV care provider's judgments about your health care." These items use a 5-point Likert-type scale, ranging from 1=strongly disagree to 5=strongly agree. Cronbach's coefficient was  $\alpha=0.82$  in the present study.

**Data analyses.** To examine the moderation effect of patient-provider race concordance on the association between HIV-related stigma dimensions in a health care setting and trust in HIV providers, separate moderation (i.e., interaction) analyses were performed using the PROCESS macro for SPSS with bootstrapping (2000 resamples).<sup>36</sup> Using multivariate regression analyses, we explored (1) if an independent relationship exists between experienced HIV-related stigma in health care settings and trust in one's HIV provider, (2) if an independent relationship exists between anticipated HIV-related stigma in health care settings and trust in one's HIV provider, and (3) if patient-provider race combinations moderate the association between patients' experienced or anticipated HIV-related stigma in health care settings and trust in their HIV provider (interaction effects). Significant interaction effects were further examined with tests for simple main effects for different race combinations. In an additional step, we conducted the same analyses, including experienced race- and ethnicity-related stigma in health care settings as a covariate, to examine whether these associations hold when controlling for race- and ethnicity-related stigma. All analyses for this study were cross-sectional; adjusted for age, education, income, and illicit drug use (in the last 6 months); and used mean scores for all variables.

## Results

We present participant characteristics in Table 1. About 90% of study participants identified as racial or ethnic minorities. Participants' mean age was about 51 years [standard deviation (SD)=9.04, range=28-81 years]; 590 participants (63.4%) described their provider as female; and 25.5% reported having engaged in illicit drug use in the last 6 months. About one-third (33.7%) of participants reported their highest level of education as high school and an average household income/year of \$6001-12,000 (35%). Mean scores were 1.15 (SD=0.40, range=1-5) for experienced HIV stigma, 1.47 (SD=0.87, range=1-5) for anticipated HIV

TABLE 1. DESCRIPTIVE STATISTICS OF THE SAMPLE (N=931)

Variable	n	%
Patient race and ethnicity		
White (non-Hispanic)	97	10.4
White (Hispanic)	49	5.3
Black (non-Hispanic)	766	82.3
Black (Hispanic)	19	2.0
HIV provider race		
White	711	76.4
Black	220	23.6
Education		
No school	2	0.2
Grades 1–6	7	0.8
Grades 7–11	282	30.3
Completed high school	314	33.7
Some college	254	27.3
Completed 4-year college	46	4.9
Attended/completed graduation school	25	2.7
Income		
≤\$6000	111	11.9
\$6001–12,000	326	35
\$12,001–18,000	139	14.9
\$18,001–24,000	77	8.3
\$24,001–30,000	51	5.5
\$30,001–36,000	41	4.4
\$36,001–75,000	98	10.5
≥\$75,000	38	4.1
Illicit drug use in the last 6 months		
Yes	237	25.5
No	693	74.4

	Mean (SD)	Range
Age, years	50.85 (9.04)	28–81
Experienced HIV stigma	1.15 (0.40)	1–5
Anticipated HIV stigma	1.47 (0.87)	1–5
Experienced race- and ethnicity-related stigma	1.13 (0.46)	1–5
Trust in HIV providers	4.24 (0.66)	1–5

SD, standard deviation.

stigma, 1.13 (SD=0.46, range=1–5) for experienced race- and ethnicity-related stigma, and 4.24 (SD=0.66, range=1–5) for trust in providers.

We tested whether the association between experienced HIV stigma in a health care setting and trust in HIV care providers was moderated by patient–provider race concordance with HIV providers. Results revealed a significant main effect of experienced stigma [ $B=-0.89$ , standard error (SE)=0.14,  $p=0.000$ , 95% confidence interval (CI) (-1.161 to -0.624)] on trust in providers, but nonsignificant main effects of the two race combination variables [White–White vs. Black patient–White provider:  $B=-0.12$ , SE=0.06,  $p=0.056$ , 95% CI (-0.24 to 0.003); and White–White vs. Black–Black:  $B=-0.06$ , SE=0.07,  $p=0.411$ , 95% CI (-0.201 to 0.082)]. The interaction effects between experienced stigma and the race dyads were significant [experienced stigma\*White–White vs. Black patient–White provider:  $B=0.71$ , SE=0.15,  $p=0.000$ , 95% CI (0.412 to 1.00); and experienced stigma\*White–White vs. Black–

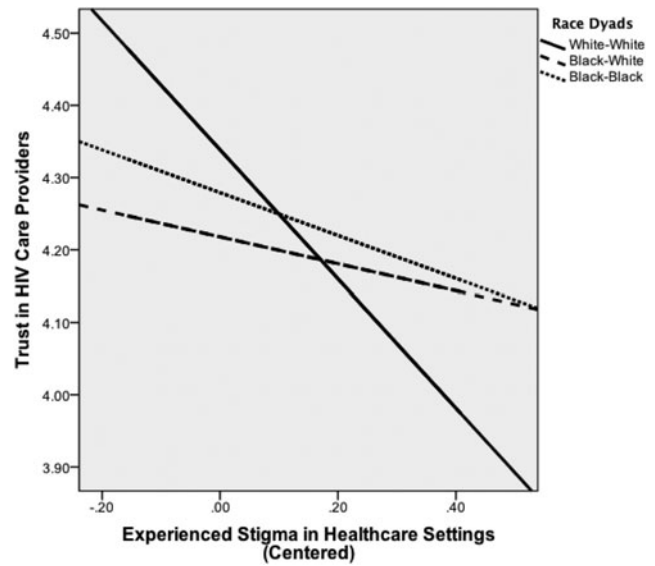
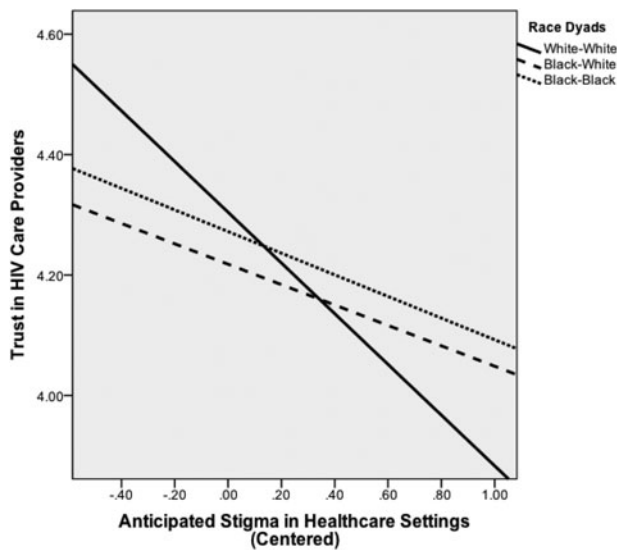


FIG. 1. Patient–provider race concordance moderates the association between HIV-related experienced stigma and trust in providers.

Black:  $B=0.60$ , SE=0.20,  $p=0.003$ , 95% CI (0.209 to 0.983)]. Simple main effects for the race dyads are presented in Fig. 1; for all three combinations, higher experienced stigma in health care settings was significantly associated with lower trust in HIV providers [White–White:  $B=-0.89$ , SE=0.14,  $p=0.000$ , 95% CI (-1.161 to -0.624); Black patient–White provider:  $B=-0.19$ , SE=0.06,  $p=0.003$ , 95% CI (-0.309 to -0.062); and Black–Black:  $B=-0.30$ , SE=0.14,  $p=0.037$ , 95% CI (-0.575 to -0.017)]; however, the significant interaction indicates that the association was stronger for the White–White combination compared with other dyads (Fig. 1).

Next, we tested whether the association between anticipated stigma in health care settings and trust in HIV providers was moderated by patient–provider race concordance with HIV providers. This analysis revealed a significant main effect of anticipated stigma [ $B=-0.42$ , SE=0.07,  $p=0.000$ , 95% CI (-0.552 to -0.289)], but nonsignificant main effects of race concordance [White–White vs. Black patient–White provider:  $B=-0.09$ , SE=0.06,  $p=0.166$ , 95% CI (-0.208 to 0.035); and White–White vs. Black–Black:  $B=-0.03$ , SE=0.07,  $p=0.652$ , 95% CI (-0.171 to 0.107)]. The interaction effects between anticipated stigma and race dyads were significant [anticipated stigma\*White–White vs. Black patient–White provider:  $B=0.25$ , SE=0.07,  $p=0.000$ , 95% CI (0.105 to 0.397); and anticipated stigma\*White–White vs. Black–Black:  $B=0.24$ , SE=0.09,  $p=0.006$ , 95% CI (0.067 to 0.415)]. Of note, when we adjusted for the effect of ethnicity (Hispanics vs. non-Hispanics), the results remain the same with significant interaction effects between HIV-related anticipated stigma and trust in HIV care providers. Simple main effect analyses indicated that for all three groups, higher anticipated stigma was significantly associated with lower trust in HIV providers [White–White:  $B=-0.42$ , SE=0.07,  $p=0.000$ , 95% CI (-0.552 to -0.289); Black patient–White provider:  $B=-0.17$ , SE=0.03,  $p=0.000$ , 95% CI (-0.232 to -0.106); and Black–Black:  $B=-0.18$ , SE=0.06,  $p=0.002$ , 95% CI (-0.293 to -0.066); see Fig. 2], with a stronger negative association for the White–White combination compared with other dyadic pairs.



**FIG. 2.** Patient–provider race concordance moderates the association between HIV-related anticipated stigma and trust in providers.

As a final step, we conducted the same analyses, including race- and ethnicity-related stigma in health care settings as a covariate. In the first moderation analysis, the interaction effect between experienced stigma and patient–provider race concordance was still significant, with a significant main effect of race- and ethnicity-related stigma on trust in HIV providers [ $B = -0.27$ ,  $SE = 0.06$ ,  $p = 0.000$ , 95% CI  $(-0.380$  to  $-0.159)$ ]. For only the White–White race combination, higher experienced HIV-related stigma was significantly associated with lower trust in HIV providers [ $B = -0.75$ ,  $SE = 0.14$ ,  $p = 0.000$ , 95% CI  $(-1.026$  to  $-0.483)$ ]. In the second moderation analysis, the interaction effect between anticipated stigma and patient–provider race concordance was also significant, again with a significant main effect of race- and ethnicity-related stigma on trust in HIV providers [ $B = -0.21$ ,  $SE = 0.05$ ,  $p = 0.000$ , 95% CI  $(-0.308$  to  $-0.116)$ ]. Simple main effect analyses indicated that for all three race combinations, higher anticipated stigma was significantly associated with lower trust in HIV providers [White–White:  $B = -0.38$ ,  $SE = 0.07$ ,  $p = 0.000$ , 95% CI  $(-0.514$  to  $-0.252)$ ; Black patient–White provider:  $B = -0.12$ ,  $SE = 0.03$ ,  $p = 0.000$ , 95% CI  $(-0.185$  to  $-0.052)$ ; and Black–Black:  $B = -0.14$ ,  $SE = 0.06$ ,  $p = 0.016$ , 95% CI  $(-0.252$  to  $-0.025)$ ].

## Discussion

Our findings suggest that there is a significant association between experienced and anticipated HIV stigma in health care settings and lower trust in providers. Results are consistent with previous studies on stigma and trust.<sup>18,26,27</sup> For instance, Kay et al.<sup>26</sup> suggested that higher levels of experienced stigma in health care settings were associated with lower levels of trust in physicians. Nyblade et al.<sup>18</sup> conducted a comprehensive assessment of stigma reduction efforts in health care facilities and revealed the persistence of stigma in clinical settings and its negative

effects on patient outcomes, and multiple other studies have provided evidence for the harmful effects of HIV-related stigma on PLHIV, those who are at higher risk for contracting HIV, and specifically on WLHIV.<sup>37–40</sup> More exploration of the effects of HIV-related stigma is warranted, particularly examination of how it interacts with resilience and how it is associated with adverse health outcomes, as well as its differential impact on women compared with men.<sup>41,42</sup>

We examined the moderating effect of patient–provider race concordance on the association between HIV-related stigma dimensions, namely experienced and anticipated stigma in health care settings and trust in HIV providers. We found significant interaction effects between patient–provider race concordance and HIV-related experienced and anticipated stigma in health care settings. Although HIV-related stigma dimensions were associated with lower trust in HIV providers for all race combinations, the strongest negative effect of stigma on trust was among WLHIV in the White–White dyad, compared with WLHIV in Black–Black and Black patient–White provider concordance. White WLHIV who had White HIV providers had a stronger negative association between experienced or anticipated stigma in health care settings and trust in providers, compared with other patient–provider race combinations. As for the Black–Black dyad, experienced and anticipated stigma in health care settings did negatively affect trust in HIV providers, but less so compared with those in the White–White dyad.

We speculate that this finding could be related to White WLHIV holding other devalued characteristics (i.e., being poor or engaging in illicit drug or opioid use) or the ubiquity of racial discrimination in the United States. People of color, including racial and ethnic minorities, may, unfortunately, be more accustomed to experiences of stigma and discrimination due to exposures related to their racial identity and therefore they may respond differently to discrimination related to other stigmatized traits, such as living with HIV. In contrast, White WLHIV, who do not routinely experience racism, may find experiences of stigma, specifically HIV-related stigma, unanticipated and potentially more upsetting than their Black peers. Rao et al.<sup>43</sup> found similar race-related differences and suggested that PLHIV likely have differential experiences of HIV-related stigma due to implicit racial bias, either related to differences in culture or interpretation of measures. Alternatively, White PLHIV may not expect stigma from their White HIV providers and so when they do encounter HIV-related stigma in health care settings, they may be internalizing and experiencing it differently compared with their non-White peers.

Our findings are consistent with previous research indicating that racial concordance between patients and providers does not necessarily ensure positive relationships and improved outcomes.<sup>21</sup> Studies have shown that racial and ethnic minority patients tend to prefer race-concordant providers due to the belief that their shared racial background will buffer them from stigma;<sup>44,45</sup> with this said, there is an insufficient number of Black and Brown clinical providers to meet the preferences of patients of color, and there is inconclusive evidence about whether achieving this stated preference produces and improves health outcomes.

Although some non-HIV studies have suggested that an association may exist between racial concordance and the likelihood of patients' seeking care when necessary,<sup>23</sup> multiple reviews of race concordance studies did not find evidence to support the notion that race concordance between patients and providers is associated with positive health outcomes for people of color.<sup>21</sup>

Taken together, findings indicate that HIV-related stigma in health care settings has a more robust association with lower trust in HIV providers than patient-provider racial concordance, and even though we uncovered a significant association between stigma dimensions in health care settings and trust in HIV providers across race dyads, effects were statistically the weakest within Black-Black dyads compared with Black patient-White provider or White-White dyads. Negative associations of HIV-related stigma in health care settings persisted, even after controlling for the effect of race or ethnicity-related stigma in health care settings.

### *Limitations*

Our data are cross-sectional, limiting our ability to infer causality. WLHIV reported their perceptions and experiences of HIV-related stigma across health care settings and reported the race of their main HIV care provider; if WIHS cohort participants interacted with multiple providers during their visits or if they reported on experiences from non-HIV health care settings, such as in emergency departments, dental offices, and other specialty providers, we were unable to disaggregate these data. Due to a small sample size, we were unable to examine concordance related to Hispanic or Latinx ethnicity. The small proportion of nonminority White women in the sample also limited our analyses, specifically our ability to conduct an assessment of White patients with Black providers. A lack of positive effect of race concordance on trust may be related to some unobserved potential confounders (e.g., intersectional stigma related to race or drug use) or other potential moderator variables (e.g., patient-provider sex concordance). To offer additional context to our findings, future research should focus on the role of other potential moderators of the association between HIV-related stigma and trust in providers, as well as on continuum of care outcomes.

To promote optimal well-being, HIV primary care and general health care settings should be stigma free; however, research has found that stigmatizing attitudes toward PLHIV are still prevalent in the United States, and these experiences are associated with poorer health outcomes. While causality cannot be inferred from our data, our findings support the need for interventions and programs to reduce stigma in health care settings to improve trust in HIV providers, which in turn may contribute to achieving desired health outcomes for PLHIV such as increased rates of medication adherence, visit adherence, and viral load suppression. Considering the deleterious association of HIV-related stigma with trust in HIV providers, which was found in this study, as well as findings from prior research suggesting that lower trust in providers is linked with negative health outcomes, eliminating HIV-related stigma in health care settings should be a high priority for public health. Continued research to understand the mechanisms through which stigma dimensions affect health is warranted.

### **Availability of Data and Materials**

Data and materials are available by request to the first author, Dr. H.B.

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### **Authors' Contributions**

J.M.T., B.T., and M.-C.K. are the principal investigators for this WIHS substudy. J.M.T. supported and guided the protocol development, analysis, and article development. H.B. provided intellectual framing for the development and revision of the article. I.Y. led the statistical analyses supported by senior-level guidance from B.T. The additional authors facilitated access to study participants at their respective study sites and provided a critical review of the article and contributed feedback. All named author(s) read and approved the final article.

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