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# Changes in Internalized Stigma and HIV Health Outcomes in Individuals New to HIV Care: The Mediating Roles of Depression and Treatment Self-Efficacy

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## Abstract

There is limited research on the effects of stigma on health outcomes among new-to-HIV care individuals. We examined the effect of changes in internalized stigma over time on health behaviors and outcomes such as viral suppression, antiretroviral therapy (ART) adherence, and visit adherence among new-to-HIV care individuals. We also analyzed the mediating effects of adherence self-efficacy and depressive symptoms in these associations. Participants were 186 persons living with HIV who initiated care at four HIV clinical sites in the United States and had diverse geographical and ethnic backgrounds. Baseline and 48-week follow-up assessments included measures of internalized stigma, ART adherence, depressive symptoms, and adherence self-efficacy. HIV visit adherence and viral load data were extracted from clinic records. Age, race, gender, insurance status, and site were controlled in all analyses. Logistic regression analyses were used to examine predictors of adherence and viral suppression. Change (decrease) in internalized stigma was calculated by subtracting follow-up internalized stigma scores from baseline scores and served as the main predictor. Mediation analyses included calculation of 95% confidence intervals for the indirect effects using bootstrapping. Decreases in internalized stigma over time were positively associated with viral suppression, ART adherence, and visit adherence. Adherence self-efficacy significantly mediated these effects of decrease in internalized stigma on all outcomes. Depressive symptoms only mediated the association between decrease in internalized stigma and ART adherence. Interventions that address internalized stigma and depressive symptoms, as well as adherence self-efficacy, may significantly improve adherence and viral suppression outcomes for individuals new to HIV care.

**Keywords:** internalized stigma, new-to-care, ART adherence, viral suppression, visit adherence

## Introduction

UNDERSTANDING UNDERLYING MECHANISMS of treatment nonadherence and viremia among people living with HIV (PLWH) is important for developing effective interventions. More importantly, for those who are newly initiating HIV medical care, addressing these mechanisms is necessary for achieving viral suppression early,<sup>1,2</sup> a crucial

requirement for promoting health and longevity for PLWH and for preventing new HIV infections in the population. HIV-related stigma is a major barrier to retention in HIV care, adherence to HIV care visits, and adherence to antiretroviral therapy (ART) among PLWH.<sup>3</sup> HIV-related stigma is a social process that involves prejudice, devaluation, discrimination, and other negative attitudes toward PLWH.<sup>4,5</sup> Several dimensions of HIV-related stigma have been defined:

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anticipated, experienced, perceived community, and internalized stigma.<sup>6,7</sup> *Internalized stigma* refers to accepting and endorsing negative attitudes about having HIV and applying those attitudes to oneself.<sup>4,7-9</sup> There is a growing body of empirical and theoretical literature suggesting that internalized stigma is a particularly important stigma dimension that negatively affects retention in HIV care, ART adherence, and visit adherence, as well as quality of life and mental health among PLWH.<sup>10-14</sup> However, much of extant research on the association between internalized stigma and HIV treatment behaviors and outcomes has been conducted with PLWH who have been in HIV care for many years and focused on ART adherence as the outcome. This study aims to contribute to this growing field of HIV stigma research by elucidating the extent to which changes in internalized HIV stigma over time are related to clinical health outcomes such as viral suppression in addition to ART adherence and visit adherence among individuals new to HIV care.

Effects of stigma may differ depending not only on levels, but also on how stigma changes over time. In addition to between-person differences in levels of stigma at a given point in time, within-person changes in stigma over time may also predict health outcomes among PLWH. Limited research on within-person changes in HIV-related stigma suggests that on average, stigma decreases over time. For instance, research suggests that HIV-related internalized stigma decreases during the first year after HIV diagnosis or over the first 2 years of ART.<sup>15,16</sup> Another study also reported that the rate of stigma events experienced by PLWH declined over a period of 12 months.<sup>17</sup> A recent study in South Africa reported that internalized stigma decreased over a period of 6 months among both ART initiators and noninitiators, suggesting that internalized stigma may naturally decline slightly over time as a result of processing and adjusting to the HIV diagnosis and gaining social support.<sup>18</sup> However, there is limited evidence indicating that changes in stigma over time are associated with health outcomes for PLWH. For example, one study in African countries found that people with decreasing stigma over a period of 1 year reported fewer medication worries.<sup>19</sup> For individuals new to HIV care, there is a need for systematic understanding of how changes in internalized stigma over time contribute to viral suppression, ART adherence, and visit adherence.

Additionally, it is important to elucidate specific mediating mechanisms in the association between change in internalized stigma over time and HIV treatment adherence and clinical health outcomes—such as viral suppression—for PLWH new to care. This insight would have implications for future intervention development for this population. Empirical and conceptual work (largely among individuals who have been in treatment for many years) suggests that low self-efficacy and depression are among the most important intrapersonal mechanisms contributing to nonadherence to HIV treatment and care.<sup>6,20-27</sup> Thus, the present study aimed to explore the mediating roles of these mechanisms in the effect of internalized HIV-related stigma in a sample of PLWH new to care. Self-efficacy, referred to as one's confidence to behave in a certain way and perform a task<sup>28</sup> is one of the major intrapersonal mechanisms in HIV treatment adherence.<sup>20,21</sup> The first year for PLWH new to care may be a critical and vulnerable time, as it involves adjusting to a life-changing diagnosis, initiating HIV treatment and care, in-

cluding regular HIV clinic visits and life-long ART,<sup>1,29</sup> which is likely to decrease a person's ability and motivation to consistently engage in HIV care.

Theoretically, internalized stigma may cause PLWH to perceive themselves as inferior, less capable, and less confident in their capacity to adhere to a treatment plan (i.e., low treatment adherence self-efficacy), which in turn may be expected to result in poor adherence to HIV treatment and care.<sup>30</sup> Supporting this hypothesis, a study found that treatment self-efficacy mediates the relationship between internalized HIV-related stigma and adherence.<sup>11</sup> Again, the first year following entry into HIV care is more likely to bring about adverse psychological health outcomes due to adjusting to living with HIV and the continuum of HIV medical care, potentially posing challenges to treatment adherence and desired clinical outcomes (e.g., viral suppression). Specifically, depression has received increasing attention as an important mediating mechanism in the association between internalized stigma and HIV treatment adherence for PLWH who have been in care for some time.<sup>13,31</sup> Thus, there is considerable (although mostly cross-sectional) evidence that internalized stigma can negatively affect HIV treatment adherence through various potential mechanisms among those who have been living with HIV for many years. However, for those newly initiating HIV care, there remains a paucity of evidence on how changes in internalized stigma affects early retention in care, ART adherence, and—most importantly—viral suppression, and on the roles of potential mediating mechanisms in these associations.

To address these gaps in the stigma literature for PLWH new to care, the current study aims to (1) investigate the effects of changes in internalized HIV stigma over time (the difference between baseline and follow-up scores of internalized stigma) on viral suppression, ART adherence, and HIV visit adherence as clinical outcomes and (2) elucidate potential mediating effects of treatment adherence self-efficacy and depressive symptoms in the association between changes in internalized stigma over time and these clinical outcomes. Given that engagement in HIV care and adherence to medications are especially vital among new-to-care HIV patients,<sup>32</sup> enhanced knowledge of how internalized stigma and other mediating mechanisms affect early retention in care, ART adherence, and viral suppression can provide important implications for developing and strengthening interventions at this vulnerable time for PLWH.

## Methods

### *Participants and procedures*

Participants were 186 PLWH initiating care at four HIV clinical sites in the United States, including Johns Hopkins University, University of Alabama at Birmingham, The University of North Carolina at Chapel Hill, and University of Washington, who participated in a larger study called “integrating ENGagement and Adherence Goals upon Entry (iENGAGE).” The details of this iENGAGE study can be found elsewhere.<sup>29,33</sup> Those who previously received outpatient HIV care were excluded from the study. Of the participants, 148 (79.6%) identified as male, 36 (19.4%) as female, and 2 (1.1%) as transgender; 112 (60.2%) were black or African American, 60 (32.3%) white, 14 (7.5%) other race/ethnicity, with a mean age of 36.33 (SD = 12.78). Participants completed baseline and 48-week follow-up measures using a computer-administered

self-interview. Data on viral load and visit adherence were obtained from clinical records. The study was approved by the Institutional Review Board at each site.

*Measures*

**Internalized HIV-related stigma.** To assess internalized HIV-related stigma, we used the 7-item Negative Self-Image subscale of the HIV Stigma Scale.<sup>34</sup> The items (e.g., “I feel guilty because I have HIV/AIDS”) are rated on a Likert-type scale ranging from 1 (strongly disagree) to 4 (strongly agree). Previous evidence demonstrated that this subscale has high internal consistency and test/retest reliability.<sup>35</sup> Higher scores indicate higher levels of internalized stigma. In the current study, Cronbach’s alpha reliability coefficient was 0.77 for the baseline scores and 0.82 for the follow-up scores.

*HIV clinical outcomes*

**ART adherence.** ART adherence was assessed with the single question,<sup>36</sup> “Thinking about the past 4 weeks, on average how would you rate your ability to take all of your HIV antiretroviral medications as your doctor prescribed” with response options ranging from very poor to excellent. Previous research suggests that this item is a valid measure of adherence.<sup>37</sup> Similar to previous studies using this measure, we employed a cutoff as less than perfect adherence versus perfect adherence—aligned with the robust negative predictive value of any degree of self-reported nonadherence.<sup>11</sup>

**HIV visit adherence.** We obtained data on adherence to HIV primary care visits from clinic records and used it as a dichotomized variable, with 1=adherence to all scheduled visits (optimal adherence), versus 0=missed at least one visit (suboptimal adherence) in the 48-week study period. Rescheduled visits were not considered as missed visit. This measure has been used successfully in previous research and associated with clinical outcomes and mortality.<sup>10</sup>

**Viral load.** Data on viral load were extracted from each participant’s last clinic visit. We used it as a dichotomized variable as not suppressed ( $\geq 200$  c/mL) versus suppressed ( $< 200$  c/mL), in accordance with treatment guidelines.

**Depressive symptoms.** The Patient Health Questionnaire (PHQ-8)<sup>38</sup> was used to measure depressive symptoms over the past 2 weeks. The PHQ-8 includes eight items rated on a 4-point Likert-type scale ranging from 0 (not at all) to 3 (nearly every day). Higher scores indicate higher depressive symptomatology. In the current study, Cronbach’s alpha was 0.91.

**Treatment adherence self-efficacy.** To assess self-efficacy in relation to treatment adherence, we used the HIV Treatment Self-Efficacy Scale.<sup>20</sup> The scale has 12 items (e.g., “Integrate your treatment into your daily routine?”) rated on a 10-point rating scale ranging from 1 (cannot do it all) to 10 (certain can do it). In the current study, this measure showed high internal consistency (Cronbach’s  $\alpha = 0.95$ ).

*Statistical analyses*

First, a series of binary logistic regression analyses were performed to determine predictors of viral suppression, ART

adherence, and visit adherence. A score for “decrease in internalized stigma” was calculated for each participant by subtracting follow-up internalized stigma from baseline internalized stigma. Decrease in internalized HIV stigma was the primary independent variable and covariates included age, race, gender, insurance status, and site. Second, mediation models were used to test whether the significant associations between decrease in internalized HIV stigma and outcome variables (viral suppression, ART adherence, visit adherence) were mediated by treatment adherence self-efficacy and depressive symptoms. Follow-up scores at 48 weeks were used for both mediator and outcome variables. The average length of time between the data collection at the 48-week assessment and the final viral load was 21 days. We calculated 95% confidence intervals (CIs) with 2000 bootstrap samples for indirect effects using PROCESS procedure. In this procedure, if the CI does not include the value zero, the indirect effect is significant, suggesting mediation.<sup>39</sup> The covariates of age, race, gender, insurance status, and site were also controlled in all of the mediation analyses. The data were analyzed using the Statistical Package for the Social Sciences (version 22; SPSS, Inc., Chicago, IL).

**Results**

Descriptive statistics of the sample are presented in Table 1. Decrease in internalized HIV stigma was a significant

TABLE 1. DESCRIPTIVE STATISTICS

	N	%
<b>Race</b>		
Black or African American	112	60.2
White	60	32.3
Other	14	7.5
<b>Gender</b>		
Male	148	79.6
Female	36	19.4
Transgender	2	1.1
<b>Ethnicity</b>		
Hispanic	12	6.5
Non-Hispanic	174	93.5
<b>Insurance</b>		
Public	92	49.5
Private	53	28.5
None	41	22
<b>Site</b>		
JHU	39	21
UAB	77	41.4
UNC	38	20.4
UW	32	17.2
	<i>Mean</i>	<i>SD</i>
Age	36.22	12.78
Internalized stigma	2.31 (2.23)	0.74 (0.77)
Depressive symptoms	5.77	5.79
Treatment adherence self-efficacy	9.05	1.50

The values in parentheses are for internalized stigma at follow-up. JHU, Johns Hopkins University; UAB, University of Alabama at Birmingham; UNC, The University of North Carolina at Chapel Hill; UW, University of Washington.

predictor of viral suppression [adjusted odds ratio (AOR)= 8.48,  $p=0.006$ , 95% CI (1.83–39.28)]. Similarly, decrease in internalized HIV stigma was a significant predictor of ART adherence [AOR=2.05,  $p=0.033$ , 95% CI (1.06–3.98)] as well as of visit adherence [AOR=2.17,  $p=0.028$ , 95% CI (1.09–4.35)]. Of the covariates, only age was significantly associated with viral suppression ( $B=0.09$ ,  $SE=0.04$ ) and with visit adherence ( $B=0.04$ ,  $SE=0.02$ ), but not with ART adherence ( $B=0.02$ ,  $SE=0.02$ ).

Next, we tested the mediating effect of treatment adherence self-efficacy in the association between decrease in internalized HIV stigma and our outcomes (viral suppression, ART adherence, and visit adherence). The indirect effect of decrease in internalized HIV stigma on all three outcomes through increases in treatment adherence self-efficacy was significant, suggesting mediation [ $B=0.65$ ,  $SE=0.53$ , 95% CI (0.12–2.23);  $B=0.29$ ,  $SE=0.18$ , 95% CI (0.05–0.76);  $B=0.24$ ,  $SE=0.15$ , 95% CI (0.05–0.62), respectively for viral suppression, ART adherence, and visit adherence; Fig. 1A–C]. We also tested the mediating effect of depressive symptoms in the association between decrease in internalized HIV stigma and viral suppression, ART adherence, and visit adherence as outcome variables. These analyses yielded nonsignificant indirect effects on viral suppression [ $B=0.26$ ,  $SE=0.43$ , 95% CI (–0.54 to 1.19)] and visit adherence [ $B=0.12$ ,  $SE=0.16$ , 95% CI (–0.21 to 0.47)], but a significant indirect effect on ART adherence [ $B=0.28$ ,  $SE=0.18$ , 95% CI (0.03–0.76); Fig. 1D].

## Discussion

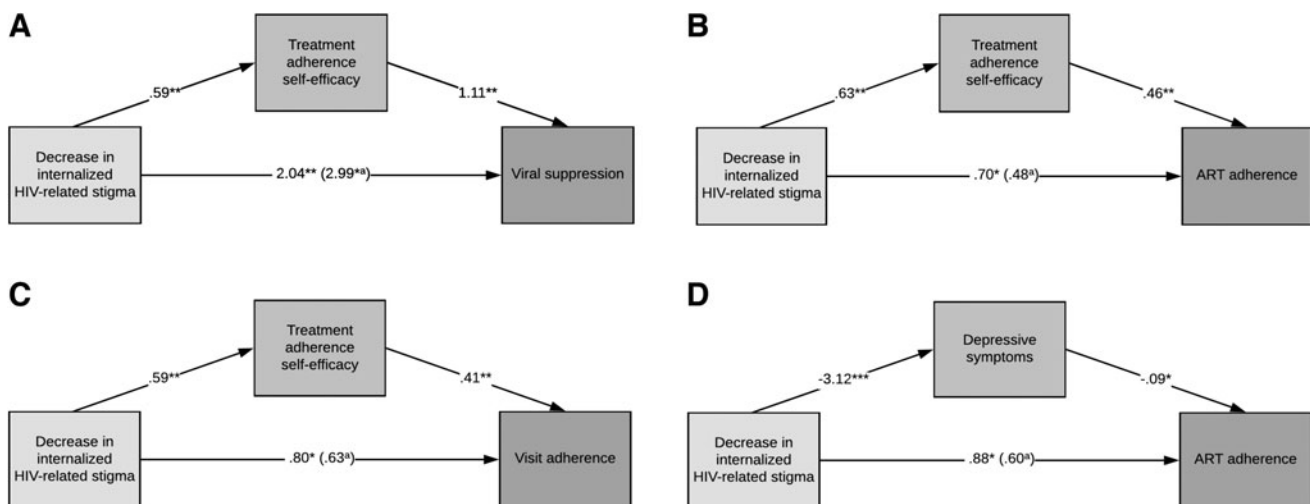
Previous studies suggest that internalized HIV-related stigma is associated with poorer medication adherence, missed clinic visits, and lower utilization of HIV care, which largely leads to undesired clinical outcomes, including detectable viral load among PLWH.<sup>10,13,40</sup> However, most research examining these associations is based on either qualitative or cross-sectional data obtained from individuals who have been living with HIV for many years. Results from

our current analyses suggest that a decrease in internalized HIV-related stigma over the first year in medical care is a significant predictor of viral suppression, ART adherence, and visit adherence. Thus, during the first year following entry into HIV care, when PLWH adjust to living with HIV and engage in HIV care, it seems essential that internalized HIV-related stigma be addressed to improve health outcomes for PLWH.

We also found that decrease in internalized HIV-related stigma over time contributes to increased levels of treatment adherence self-efficacy, which in turn results in positive impacts on viral suppression, ART adherence, and visit adherence. This finding is consistent with earlier findings that low adherence self-efficacy mediates the association between internalized stigma and poorer ART adherence for individuals who have been living with HIV for many years.<sup>11,31</sup> Initiating HIV treatment and care can be an overwhelming process, which includes adjustment to living with HIV (a lifetime commitment), decisions about disclosure of HIV status to others, initiation of ART, taking HIV medications daily and regularly, and attending regular HIV clinic visits.<sup>1,41,42</sup> Results suggest that PLWH who internalize HIV-related stigma have lower confidence in their ability to adhere to treatment regimen, leading to lower medication adherence, missed clinic visits, and eventually viremia.

Another important finding of this study was that depressive symptoms mediate the association between decrease in internalized HIV stigma and ART adherence, suggesting that decreases in internalized HIV-related stigma may lead to lower levels of depressive symptoms, which in turn can positively affect adherence to ART. This finding is also in agreement with previous studies, which have suggested that the associations between internalized stigma and HIV-related health outcomes may work through the pathway of depression.<sup>31,43</sup>

An understanding of these associations and mechanisms has the potential to inform interventions to maximize their impacts on retention in care, ART adherence, and viral suppression, and also help mitigate the psychological and



**FIG. 1.** (A–D) Treatment adherence self-efficacy and depressive symptoms mediate the effect of decrease in internalized HIV-related stigma on viral suppression, ART adherence, and visit adherence. <sup>a</sup>When treatment adherence self-efficacy or depressive symptoms are in the model. \* $p<0.05$ , \*\* $p<0.01$  ( $N=137, 126, 146$ , and  $119$  for A–D, respectively). ART, antiretroviral therapy.

physical sequelae of internalized HIV-related stigma for PLWH. The results of the present study suggest that in addition to addressing internalized HIV-related stigma, interventions can also target treatment adherence self-efficacy and depressive symptoms to enhance adherence to care and viral suppression. Blocking the path from internalized stigma to depressive symptoms or adherence self-efficacy, or blocking the path from low self-efficacy or depressive symptoms to HIV-related health behaviors and outcomes may also be useful intervention strategies. For instance, at the individual level, cognitive-behavioral therapy (CBT) can be particularly effective in decreasing internalized stigma and depressive symptoms, as well as building skills for HIV treatment adherence, and promoting medication adherence among PLWH.<sup>44-46</sup> Moreover, targeted interventions with strategies to help with safe HIV disclosure and building social support, which are important to the development of self-efficacy,<sup>28,47</sup> may be effective in developing adaptive health behaviors and outcomes, such as improved medication adherence and viral suppression.

Even though individual counseling or therapies such as CBT are likely to be useful, they place the burden of ending HIV stigma on the individual and do not address social and structural drivers of stigma.<sup>48,49</sup> Thus, community- or structural-level approaches, including national communication campaigns,<sup>50</sup> mass media programs,<sup>51,52</sup> support groups,<sup>53,54</sup> personal contact with PLWH programs,<sup>53,55</sup> faith- or church-based interventions,<sup>56,57</sup> public health programs,<sup>58</sup> and stigma-reduction interventions in health care settings,<sup>59,60</sup> can be effective in reducing HIV-related stigma.<sup>53,61</sup> Lastly, even though internalized stigma tends to decrease over time,<sup>15,16,18</sup> the first year of HIV care is of crucial importance in engaging in HIV care and developing adherence skills.<sup>29,33</sup> As such, targeting HIV-related stigma immediately after initial entry into HIV care among PLWH using appropriate approaches may contribute to facilitating treatment adherence and retention in care, and thereby to achieving desired clinical outcomes (e.g., viral suppression).

It is important to note that the association between internalized HIV-related stigma and depression may be bidirectional.<sup>13</sup> There may be other potential mechanisms (e.g., other dimensions or sources of stigma) that could explain the association between internalized stigma and viral suppression and visit adherence. Research focusing on mediating mechanisms of different types and dimensions of stigma would significantly contribute to our understanding of what psychosocial components should be included in interventions to reduce internalized stigma and associated negative effects on health outcomes.

The current study has several limitations. First, we used a self-report measure for ART adherence, which may be subject to reporting and social desirability biases. Furthermore, in mediation analyses, it is likely that there are unobserved potential confounders and mediator variables associated with both observed mediators and outcome variables. Thus, future studies would add to our understanding of other mechanisms which mediate the effects of internalized stigma on health outcomes. Finally, the participants of the study were recruited from four sites affiliated with major academic health centers, which are not representative of all PLWH in the United States. Therefore, our results only may be generalized

to PLWH in similar clinical settings. On the other hand, it is a strength that participants in our sample had diverse geographical and ethnic backgrounds.

Overall, the present study suggests that during the first year following initial entry into HIV care, decrease in internalized HIV-related stigma contributes to HIV treatment adherence and viral suppression, mediated through increased treatment adherence self-efficacy and depressive symptoms. This information can be used for future intervention development and medical and supportive service provision, particularly within a period when PLWH are initiating HIV treatment process.

### Author Contributions

All authors contributed to the study conception and design. Data analyses were performed by (B.T.) and (I.Y.). The first draft of the article was written by (I.Y. and B.T.) and all authors contributed to the article. All authors read and approved the final article.

### Author Disclosure Statement

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