# Cumulative Effects of Stigma Experiences on Retention in HIV Care Among Men and Women in the Rural Southeastern United States

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# Abstract

The stigmatization of HIV infection impedes every step along the HIV continuum of care, particularly care engagement and retention. The differential effects of various sources of stigma on retention in HIV care have been the subject of limited research. We examined the accumulation of HIV stigma experiences over 1 year in relationship to treatment retention among 251 men and women marginally engaged in HIV care in the southeastern United States. Results showed that cumulative stigma experiences predicted poorer retention in care, with greater stigma experiences related to less consistency in attending scheduled medical appointments. HIV stigma originating from family members and acts of overt discrimination were the most frequently experienced sources of stigma and were most closely associated with disengagement from HIV care. In addition, analyses by gender indicated that retention in care for men was impacted by stigma to a greater extent than among women. These findings reaffirm the importance of HIV stigma as a barrier to HIV care and provide new directions for interventions to mitigate the negative effects of stigma on patients who are not fully engaged in HIV care. Clinical trials registration NCT104180280.

Keywords: HIV treatment, retention in care, HIV stigma, health disparities

# Introduction

T HE SUCCESS OF combination antiretroviral therapies (ART) hinges on persistent engagement in HIV care.<sup>1,2</sup> The CDC estimates that 26% of people diagnosed with HIV in the United States are not fully engaged in care, with as many as 51% of those who were once engaged in care becoming disengaged.<sup>3</sup> Snapshots of care engagement and retention, that is whether patients are engaged in care at a given point in time, do not capture the dynamic processes of care engagement, retention, disengagement, and reengagement.<sup>4</sup> As few as half of patients who initiate reengagement in care succeed; and patients who are already HIV viral suppressed are more likely to remain in care.<sup>5</sup>

Long-term retention in care is essential to achieving HIV treatment and prevention goals.<sup>6</sup> Although efforts to improve retention in care are cost-effective and deemed a public health priority,<sup>7</sup> there are a myriad of challenges that impede engagement and retention in HIV care across cultures,<sup>4</sup> with evidence from multiple countries finding that HIV stigma impedes engagement and retention in care.<sup>8,9</sup>

Stigma is a robust barrier to remaining in HIV care. Typically considered a complex phenomenon, stigma socially devalues and discredits individual characteristics, attributes, and behaviors.<sup>10</sup> Since the beginning of the HIV pandemic, stigma has undermined every step along the HIV continuum of care.<sup>11–15</sup> In South Africa, the internalization of HIV stigma is related to avoidant coping and delayed initiation of ART.<sup>16</sup> Experiencing HIV stigma is also associated with uncontrolled HIV (e.g., detectable viral load), missed clinic visits, poor clinic visit constancy, and disengagement from care.<sup>17</sup>

Enacted HIV stigma, defined as acts of overt and subtle discrimination experienced by people living with HIV, can be salient and have lasting adverse effects.<sup>18</sup> HIV stigma originating from families and its consequential undermining of family support have emerged as a particularly potent predictor of poor engagement in HIV care.<sup>19</sup> There is also evidence that patients' experiences with enacted stigma interact with their connection to care providers, such that people who experience more HIV stigma are less connected to their providers and consequently have poorer retention in care.<sup>20</sup> Few studies, however, have examined stigma

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experiences in relationship to care retention among patients who may be at risk for disengagement from care, specifically patients who are newly engaged, reengaged, or at risk for treatment failure.

This study examined enacted stigma experiences stemming from multiple sources over the course of 1 year in relationship to their cumulative effects on retention in HIV care. We focused on people at high risk for treatment disengagement, specifically newly diagnosed patients, patients who had previously disengaged and were returning to care, and patients identified by providers as marginally engaged in care and at risk for treatment failure.

Further, given that stigma occurs to a greater degree in rural areas relative to urban centers,<sup>21,22</sup> we conducted our study at a public clinic serving a rural area in the southeastern United States. We hypothesized that the accumulation of enacted stigma experiences over 1 year would be associated with disengagement from HIV care and that the strongest predictor of disengagement from HIV care would be family-related enacted stigma experiences.

### Methods

### Participants and procedures

Participants were 175 men and 76 women recruited between September 2015 and December 2017 from a publicly funded HIV clinic in central Georgia, serving a small city and surrounding rural areas. Data from these participants with some overlapping measures have been reported in previous research.<sup>23</sup> A total of 375 patients were referred and contacted to explain the study and 251 agreed, yielding a 67% acceptance rate.

Following informed consent, participants completed a computerized interview and provided permission for the researchers to retrieve their HIV viral loads and their medical appointment records from electronic clinic charts. All individuals received behavioral health counseling as part of their participation. Participants were called monthly for health monitoring interviews and were compensated for their time to complete measures over the course of the year with up to \$580 cash dispensed through ATM card. The University of Connecticut and Mercer University Institutional Review Boards approved all procedures. These data are from a trial registered at clinicaltrials.gov NCT104180280.

# Measures

We utilized data collected within a 12-month period to examine the associations between cumulative enacted stigma experiences and retention in care. Cumulative HIV-related enacted stigma was aggregated from stigma events collected monthly for 1 year. Our approach was to monitor stigma monthly to capture repeated events because stigma is highly impactful and experienced sporadically.<sup>24,25</sup>

# Audio computer-administered self-interviews

We collected participant demographic characteristics (i.e., gender, sexual orientation, race, age, and years of education), and the year and place they tested HIV positive. Participants also completed the full 20-item CESD (Centers for Epidemiological Studies Depression) scale to assess symptoms of depression.<sup>26</sup> Items focused on how often participants had

specific depression-related thoughts, feelings, and behaviors in the last 7 days. Responses were 0=0 days, 1=1-2 days, 2=3-4 days, and 3=5-7 days. Scores range from 0 to 60 and scores greater than 16 indicate possible depression, alpha=0.90. Alcohol use at baseline was assessed with the Alcohol Use Disorders Identification Test (AUDIT), a 10-item scale designed to measure alcohol consumption and identify risks for alcohol abuse and dependence.<sup>27</sup> AUDIT scores between 1 and 7 represent moderate drinking and scores 8 and greater indicate possible hazardous alcohol use.<sup>28</sup> We also calculated the distance in miles that participants resided from the clinic using ArcGIS software.

#### Medical records chart abstraction

HIV viral load. Laboratory reports of blood plasma HIV viral load most proximal and within 3 months of the baseline assessment were abstracted from electronic medical records. In accordance with HIV treatment guidelines,<sup>29</sup> we used the clinically recorded value with a threshold of <20 copies/mL to define suppressed (undetectable) viral load.

Retention in care. Retrospective chart reviews at the end of the study were performed to determine whether patients were retained in care. Electronic medical records were examined over the 12 months during which assessments were collected with an additional 6 months of post-assessment period, a total of 18 months to assess care retention. Coding retention in care for an additional 6 months past the final follow-up assessment encompasses the time period during which stigma may have influenced this outcome.

Records were coded for number of clinical/medical appointments scheduled, attended, and not attended. Participants with records marked as "discontinued care" were defined by the clinic as disengaged from care. Typically at the clinic, patients who had not been seen for clinical services with missed appointments over 6 months are defined as disengaged from care. Patients transferred to other providers and patients who died are treated distinctly in the medical records and were not coded as disengaged from care.

### Monthly phone assessments: enacted stigma

At each monthly phone interview, we assessed enacted stigma using an adaptation of the HIV Stigma Mechanisms Scale.<sup>18,30</sup> We used seven items to assess experiences of enacted stigma each month. We purposefully selected a broad array of stigma experiences to reflect family relationships, experiences of discrimination, and denial of services, including health care (see Results section for exact wording of the seven items). We administered the enacted stigma items at each of the 12-monthly telephone assessments.

Stigma experiences were asked each month referring to the preceding 30 days with responses indicating yes the experience occurred, or no the experience did not occur in the previous month. We summed the stigma experiences for all available assessments to create a cumulative composite representing the frequency of the seven stigma experiences occurring during the course of the 12 months. Cumulative stigma experiences were examined within each of the seven different stigma experiences, scores having a potential range from 0 to 12, as well as for the enacted stigma experiences across 12 months, with scores ranging from 0 to 84.

# Data analyses

# Results

We conducted descriptive analyses of demographic and health characteristics for individuals identified in their medical records as retained (N=193) and disengaged (N=58) from care. Statistical significance between groups was analyzed using contingency table  $\chi^2$  tests for categorical variables and independent *t*-tests for continuous variables. Cumulative enacted stigma experiences over the 12-month observation period were examined for the proportion of participants who experienced at least one stigma event, the mean number of stigma, and the mean number of enacted stigma events for the entire sample.

We tested the main study hypothesis that cumulative enacted stigma experiences would be associated with disengagement from HIV care using Poisson regression for the association between the cumulative number of stigma events and disengagement from care. We subsequently tested models for each of the seven different enacted stigma experiences. All models were tested with robust estimators, included gender as a factor, and controlled for participant age, the distance participants lived from the clinic, depression scores, and alcohol use. All statistical tests defined significance as p < 0.05. The sample included 131 (52%) patients who had fallen out of HIV care and were returning to care, 47 (19%) patients who were newly diagnosed with HIV and were therefore new to HIV care, and 73 (29%) patients referred by their physician or nurse due to HIV viral load rebound or nonadherence to ART. The sample was predominantly male (70%) and African American (83%). Among men, 96 (55%) identified as gay or bisexual. Nearly half (46%) of participants had no source of employment and 71% had annual incomes under \$10,000. On average, participants had been living with an HIV diagnosis for more than 10 years, with 44% demonstrating HIV viral suppression from medical chart data. Two out of three participants reported active use of alcohol at baseline and the sample median CESD score was over the cutoff of 16 for considering probable depression.

Results showed that 58 (23%) participants disengaged from care over the course of the 18 months of medical record chart abstraction. Table 1 shows the demographic and health characteristics of participants who were retained and those who were disengaged from care. The only two distinguishing characteristics between patients retained and those who disengaged from care were age and the distance participants

 TABLE 1. CHARACTERISTICS OF PARTICIPANTS WHO WERE RETAINED IN CARE

 AND THOSE WHO DISENGAGED FROM CARE

	Retained in care, N=193		Disengaged from care, N=58		
Characteristic	Ν	%	Ν	%	$\chi^2$
Gender					
Gay/bisexual identified men	71	37	25	43	0.7
Heterosexual identified men	61	32	17	29	
Women	60	31	16	28	
Transgender	7	4	3	5	0.2
Race					
White	20	10	12	21	4.7
African American	165	86	43	74	
Other	7	4	3	5	
Unemployed	154	80	46	79	0.4
Income less than \$10,000	139	71	41	71	3.3
Income between \$10,000 and 20,000	38	20	8	14	
Income greater than \$20,000	16	9	9	15	
Viral load undetectable <sup>a</sup>	75	43	24	46	0.2
Viral load detectable	101	57	28	54	
Care status reengaging in care	101	52	20	52	0.8
Newly diagnosed	34	18	13	22	
Provider identified at risk	58	30	15	26	
	М	SD	М	SD	t
Age	43.4	12.3	37.9	11.6	2.9**
Years since HIV diagnosis	12.1	8.9	10.4	7.7	1.2
Distance in miles residing from clinic	1.2	11.7	16.4	20.5	2.3*
AUDIT Alcohol score	4.0	5.4	4.2	6.8	0.2
CES-depression score	21.1	10.3	21.7	9.9	0.4
Clinic appointments attended	4.6	1.9	3.1	1.5	4.9**
Clinic appointments no-showed	3.0	1.9	2.9	1.8	0.5
% Clinic appointments attended	66.1	22.3	55.5	19.4	3.1**

<sup>a</sup>Viral load was unavailable for 23 participants.

\**p*<0.05, \*\**p*<0.01.

AUDIT, Alcohol Use Disorders Identification Test; CES, Centers for Epidemiological Studies; SD, standard deviation.

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lived from the clinic; patients who disengaged from care were significantly younger and lived significantly farther from the clinic than those who were retained. As would be expected, participants who disengaged from care had fewer clinic appointments and a higher rate of not showing for appointments.

# Enacted stigma experiences

A total of 109 (47%) participants reported experiencing at least one enacted stigma event over the 12-month observation period. For the entire sample, including those who did not report any stigma experiences over the year, the mean number of stigma experiences was 2.6 (SD = 5.8) (Table 2). Among participants who experienced at least one enacted stigma event, the average number of stigma experiences over the year was 5.7 (SD = 7.5). One in five participants reported at least one occurrence of their family treating them differently because they have HIV and one in four participants reported experiencing at least one act of discrimination. As shown in Fig. 1, the most commonly experienced stigma events originated from family and acts of discrimination, with more than one in four participants reporting at least one such experience over the year. Less common were stigma experiences in health care, denial of services, concealing one's health care, and people avoiding touching participants.

## Enacted stigma experiences and retention in care

Poisson regression models for retention in care and gender, controlling for participant age, distance participants lived from the clinic, depression scores, and alcohol use showed a significant association between retention in care and number of stigma experiences over the year, Wald's  $\chi^2 = 11.8$ , p < 001. As shown in Table 2, participants who disengaged from care experienced a greater number of stigma events over the year. In addition, women (mean = 2.9, SD = 7.4) reported a greater number of stigma experiences than men (mean=2.4, SD=5.1), Wald's  $\chi^2$ =6.8, p<0.01. The interaction between retention in care and participant gender was also significant, Wald's  $\chi^2 = 10.4$ , p < 0.01; women who disengaged from care experienced only slightly more stigma events (mean = 3.20, SD = 9.71) than women retained in care (mean = 2.82, SD = 6.45), whereas men who disengaged from care (mean = 3.66, SD = 5.58) experienced 43%more stigma events as men who were retained in care (mean = 2.07, SD = 4.93).

Examining each of the seven sources of enacted stigma experiences, controlling for all covariates, patients who disengaged from care experienced more family avoidance and family members treating them differently because of their HIV status, and more acts of discrimination (Table 2).

# Discussion

This study found high rates of treatment discontinuation among patients who were deemed to be at risk for disengagement from care. We found that over an 18-month period, more than one in five (23%) participants was disengaged from HIV care. Younger participants residing farther from the clinic were more likely to disengage from

TABLE 2. ENACTED STIGMA EXPERIENCES OVER THE 12-MONTH STUDY AMONG PARTICIPANTS WHO WERE RETAINED IN CARE AND THOSE WHO DISENGAGED FROM CARE

Enacted stigma experience items		Retained in care, N=193		Disengaged from care, N=58	
		SD	М	SD	Wald $\chi^2$
Because of your HIV status, did family members avoid you? Among those experiencing this stigma	0.4 2.1	1.1 1.8	0.8 3.3	2.1 3.4	14.2**
Because of your HIV status, did family members treat you differently? Among those experiencing this stigma	0.4 2.3	1.3 2.1	0.9 2.9	2.1 3.1	12.4**
Did people discriminate against you because of your HIV status? Among those experiencing this stigma	0.5 2.3	1.3 2.1	1.0 2.8	1.9 2.3	4.6*
Were you denied services because of your HIV status? Among those experiencing this stigma	0.2 1.8	$\begin{array}{c} 0.6 \\ 1.1 \end{array}$	0.2 1.5	0.6 1.2	2.9
Because of your HIV status, did health care workers not listen to your concerns?	0.3	0.8	0.2	0.6	0.4
Among those experiencing this stigma	1.7	1.1	1.4	1.0	
Did you avoid going to a clinic or health care provider because you did not want others to know your HIV status?	0.2	1.0	0.1	0.4	3.5
Among those experiencing this stigma	3.1	2.3	1.2	0.4	
Did people avoid touching you because of your HIV status? Among those experiencing this stigma	0.2 1.7	$\begin{array}{c} 0.6 \\ 1.0 \end{array}$	0.2 1.6	0.9 1.7	0.6
Any enacted HIV stigma experience Among those experiencing this stigma	2.3 5.2	5.4 7.2	3.5 6.2	6.9 8.3	13.7**

Items shown as presented to participants; responses were Yes, did occur, and No did not occur. Enacted stigma experiences were asked each month and could be reported more than once during the 12-monthly assessments; Poisson regression models adjusted for gender, age, depression, and alcohol use.

 $\frac{1}{p} < 0.05, \ **p < 0.01.$ 

SD, standard deviation.



FIG. 1. Percentages of participants experiencing HIV-related stigma events for those retained in care and disengaged from care.

care. Participants who ultimately disengaged from care had only attended 55% of their scheduled clinic appointments, significantly fewer than those retained in care. It should be noted, however, that only 66% of clinic appointments were kept by participants who were retained in care.

Confirming our main study hypothesis and consistent with past research,  $^{20,31-33}$  we found that the cumulative effect of enacted stigma experiences over 1 year was associated with disengagement from HIV care. However, we also found a significant interaction between care disengagement and gender for the number of enacted stigma experiences. Comparisons of women retained in care and those disengaged from care indicated that there was no significant difference in stigma experiences. In contrast, men who disengaged from care experienced far more stigma than men who were retained. This interaction occurred in the absence of gender differences in care engagement and suggests that stigma may be a relatively more potent impediment to care retention for men compared to women living with HIV in this setting. One potential explanation for this finding is the intersection of HIV stigma with other stigmatized social identities, such as sexual orientation. For example, men who have sex with men may experience the unique intersection of HIV and homophobia that may compound their experience of stigma.<sup>34,35</sup>

Although we did not observe an association between having had male sex partners and retention in care, we also did not measure intersectional stigmatized identities per se.<sup>34</sup> Previous research has shown that the intersection of race and gender in the experience of subtle forms of discrimination, for example, poses unique barriers to HIV care for women.<sup>36</sup> An alternative explanation for the observed interaction of retention in care and gender is a potential resilience among women in terms of managing stigma. Thus, the lack of evidence for a detrimental effect of cumulative stigma on retention in care for women may reflect variables not measured in our study, such as anticipated stigma,<sup>37</sup> neighborhood characteristics and community support,<sup>38</sup> and relationships with health care providers.<sup>5,31</sup> Research is needed to further

examine the basis for the observed gender differences and the impact of HIV stigma on men and women with respect to retention in care.

We also confirmed our hypothesis that family-related stigma experiences would be robust predictors of disengagement from care. Participants who disengaged from care reported significantly more experiences where family members avoided them and treated them differently because of their HIV status. Disengagement from care was also associated with an array of discrimination experiences, although at smaller magnitudes than seen for familial stigma. Our findings are therefore consistent with research focused on women living with HIV, demonstrating the importance of family support in facilitating retention in HIV care.<sup>19</sup> Stigma experiences originating from family may be particularly detrimental because family may otherwise serve as a supportive buffer against stigma stemming from other sources.

Results of this study should be interpreted in light of its methodological limitations. Although we sampled a clinic serving a broad geographical area within a state with high HIV prevalence, the sample was one of convenience and cannot be considered representative of people living with HIV in this region. In addition, the study was conducted in just one state in the southeastern United States, and is therefore geographically constrained. Although more than 65% of people living with HIV in rural areas of the United States reside in southern states and more than half of people living with HIV in Georgia reside outside of major metropolitan areas,<sup>39</sup> our sample cannot be assumed presentative of people living with HIV in southern rural states. Our medical records of viral load data also did not allow us to examine this important health marker in relationship to retention in care because viral loads were missing for those with missed appointments and disengagement from care. Our study also relied on self-reported measures of stigma, which themselves may be prone to underreporting. We also studied only a limited number of stigma events. Although we selected salient experiences, the impact of other sources of stigma as

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well as less salient microaggressions should be included in future studies.<sup>40</sup> It also should be noted that our relatively small sample size precluded examining potential multiple moderators of associations, such as mental health and substance use. Finally, although our study design was prospective in that we examined the cumulative effects of enacted stigma experiences collected over the course of 1 year and retention in care for 18 months, these findings should not be considered causal or directional, given that we did not model temporal associations among variables. With these limitations in mind, we believe that these study findings have implications for designing interventions aimed to address HIV-related stigma, to improve retention in HIV care.

Ameliorating the adverse effects of HIV stigma is a priority in efforts to achieve universal HIV diagnosis, treatment, and prevention goals.<sup>8,41</sup> Among people receiving HIV care in the rural southeastern United States, our findings suggest that HIV stigma experiences may have a cumulative effect on retention in care, especially among men, and that stigma from family and acts of discrimination may be of particular importance to address for improving retention in care.

We are not aware of any intervention that has been effective in addressing HIV stigma to improve retention in HIV care. However, interventions have focused on addressing barriers to HIV disclosure in managing stigma more generally, with some approaches demonstrating positive results on health outcomes, including reducing sexual HIV transmission risks, more effective coping, and improvement in mental health.<sup>42,43</sup> Interventions have focused on building supportive networks among men at risk for as well as living with HIV to improve engagement in prevention and care services.<sup>44</sup> Social media and other electronic communication platforms have also opened avenues for building social support to foster engagement in health care.<sup>45</sup> These models may offer a path toward improving HIV care retention for people living in stigmatized environments.

#### Author Disclosure Statement

No competing financial interests exist.

#### Funding Information

The study was approved by the University of Connecticut Institutional Review Board Protocol H14-184GDPH and all participants gave written informed consent. This project was supported by National Institute of Alcohol Abuse and Alcoholism Grant R01-AA023727.

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