

Published in final edited form as:

*AIDS Behav.* 2013 June ; 17(5): 1785–1795. doi:10.1007/s10461-013-0437-9.

## HIV Stigma Mechanisms and Well-Being among PLWH: A Test of the HIV Stigma Framework

Valerie A. Earnshaw<sup>1</sup>, Laramie R. Smith<sup>2,3</sup>, Stephenie R. Chaudoir<sup>3,4</sup>, K. Rivet Amico<sup>3</sup>, and Michael M. Copenhaver<sup>3,5</sup>

<sup>1</sup>School of Public Health and the Center for Interdisciplinary Research on AIDS; Yale University, New Haven CT USA

<sup>2</sup>Department of Psychology; University of Connecticut, Storrs CT USA

<sup>3</sup>Center for Health, Intervention, and Prevention; University of Connecticut, Storrs CT USA

<sup>4</sup>Department of Psychology; College of the Holy Cross, Worcester MA USA

<sup>5</sup>Department of Allied Health Sciences; University of Connecticut, Storrs CT USA

### Abstract

The current work evaluates the HIV Stigma Framework in a sample of 95 people living with HIV recruited from an inner-city clinic in the Bronx, NY. To determine the contributions of each HIV stigma mechanism (internalized, enacted, and anticipated) on indicators of health and well-being, we conducted an interviewer-delivered survey and abstracted data from medical records. Results suggest that internalized stigma associates significantly with indicators of affective (i.e., helplessness regarding, acceptance of, and perceived benefits of HIV) and behavioral (i.e., days in medical care gaps and ARV non-adherence) health and well-being. Enacted and anticipated stigma associate with indicators of physical health and well-being (i.e., CD4 count less than 200 and chronic illness comorbidity respectively). By differentiating between HIV stigma mechanisms, researchers may gain a more nuanced understanding of how HIV stigma impacts health and well-being and better inform targeted interventions to improve specific outcomes among people living with HIV.

### Keywords

HIV; stigma; HIV Stigma Framework; health; discrimination

## INTRODUCTION

HIV stigma, or social discrediting and devaluation associated with HIV (1), remains a significant barrier to efforts aimed curbing the HIV epidemic throughout the world. Essentially, HIV stigma is a social or structural level phenomenon that exists when labeling, stereotyping, status loss, and discrimination occur within a power structure (2). HIV stigma ultimately maintains and reproduces social inequalities, particularly those associated with class, race, gender, and sexuality (3). A wealth of evidence demonstrates that the social phenomenon of HIV stigma has a downstream, negative impact on the health of individual people living with HIV [PLWH; for a recent meta-analysis, see (4)]. However,

understandings of how individual PLWH are affected by HIV stigma in ways that ultimately impact their health have remained limited for much of the epidemic (5).

To address this limitation of the literature and bridge conceptualizations of HIV stigma at the structural and individual levels, Earnshaw and Chaudoir proposed the HIV Stigma Framework (6). This framework suggests that the social phenomenon of HIV stigma impacts individual PLWH via a series of HIV stigma mechanisms, which are distinct psychological responses to the knowledge that they possess a socially devalued characteristic. The HIV Stigma Framework proposes that PLWH experience the stigma mechanisms of internalized, anticipated, and enacted HIV stigma. Internalized HIV stigma refers to endorsing negative feelings and beliefs associated with HIV and applying them to the self. HIV is similar to many other stigmatized characteristics in that it can be gained during one's lifetime (7). People who acquire a devalued characteristic such as HIV often first learn about and potentially endorse negative feelings and beliefs about the characteristic from the perspective of a person living without the characteristic. After acquiring the characteristic, the process of confronting these previously held feelings and beliefs may result in internalized stigma. Therefore, internalized HIV stigma may be a common reaction to gaining HIV. In contrast to internalized HIV stigma, anticipated and enacted HIV stigma involve experiences with others. Anticipated HIV stigma involves expectations of discrimination, stereotyping, and/or prejudice from others in the future due to one's HIV. Enacted HIV stigma involves experiences of discrimination, stereotyping, and/or prejudice from others in the past or present due to one's HIV.

Earnshaw and Chaudoir hypothesize that differentiating between these individual-level HIV stigma mechanisms within research is important to advance understandings of how HIV stigma impacts specific health and well-being outcomes among PLWH (6). That is, internalized, anticipated, and enacted HIV stigma may be differentially associated with specific affective, behavioral, and physical indicators of health and well-being. Although there is some evidence in support of this hypothesis from research involving other stigmas [e.g., among gay men; (8)], it has yet to be empirically tested among PLWH. In the current paper, we provide the first empirical test of the HIV Stigma Framework among PLWH by evaluating whether HIV stigma mechanisms are differentially associated with critical indicators of affective, behavioral, and physical health and well-being. Insight into which stigma mechanisms drive specific health and well-being outcomes among PLWH could help better target interventions to improve specific outcomes of interest.

### Differentiating between HIV Stigma Mechanisms

Figure I depicts our hypotheses regarding associations between HIV stigma mechanisms and indicators of health and well-being among PLWH. The circles at the top of the figure represent the general association between HIV stigma mechanisms and outcomes proposed by the HIV Stigma Framework. Paths A – E, connecting HIV stigma mechanisms and indicators of health and well-being, represent the hypotheses that are evaluated within the current work. We also include bi-directional arrows to represent potential correlations between HIV stigma mechanisms as well as correlations between indicators of health and well-being. Past work suggests that internalized, anticipated, and enacted stigma are correlated (9,10). For example, PLWH who experience greater enacted HIV stigma may also experience greater internalized HIV stigma. Past work further suggests that affective, behavioral, and physical health and well-being are correlated (11,12). PLWH who feel more helpless about their HIV may also attend fewer medical care visits.

Internalized HIV stigma may have particularly strong associations with affective and behavioral indicators of health and well-being among PLWH (paths A and B in Figure I). Internalized HIV stigma encompasses feelings of being “less than” others, dirty or unclean,

and/or deserving of negative outcomes due to having HIV. Not surprisingly, meta-analytic evidence suggests that internalized stigma is associated with a range of negative mental health factors, including greater depressive symptoms, greater psychological distress, lower self-esteem, and lower well-being (13). Although some people living with chronic illnesses develop and maintain positive cognitions regarding their disease [e.g., seeing disease as opportunity to shift life priorities and goals; (14)], PLWH who feel shameful about their HIV status may struggle to develop or maintain positive cognitions about their HIV. Instead they may feel greater helplessness regarding, lower acceptance of, and perceive fewer benefits of living with HIV. Evidence further suggests that internalized HIV stigma is associated with low implementation of HIV-related health behaviors, including suboptimal antiretroviral adherence (15). PLWH who have internalized stigma may not engage in health behaviors because they feel that they do not deserve care and/or because they want to avoid thinking about their HIV status (16).

Anticipated HIV stigma may have particularly strong associations with behavioral and physical indicators of health and well-being among PLWH (paths C and D in Figure I). PLWH may expect poor health care, social rejection, job loss, physical violence, and other forms of poor or unfair treatment regardless of whether they have had these experiences in the past. These expectations can shape how PLWH interact with others. For example, evidence from people living with a variety of chronic illnesses demonstrates that those who anticipate greater stigma from healthcare providers are less likely to access care (10). Likewise, PLWH who anticipate stigma may be less likely to disclose their HIV status to others with whom they have sex (7). In each case, PLWH who anticipate HIV stigma may avoid certain interactions wherein they expect to be treated poorly due to their HIV status. These expectations may also take a physical toll on PLWH. Longitudinal work demonstrates that gay men living with HIV who anticipate stigma (i.e., are more sensitive to rejection) experience accelerated HIV disease progression (17). Anticipated stigma may overburden physical functioning to the extent that it acts as a chronic stressor (18). Stress impacts the physical health of PLWH via the neuroendocrine (i.e., HPA axis) and sympathetic nervous system pathways (19). A growing body of research demonstrates that stress is associated with HIV disease progression, including decreases in CD4 T lymphocytes (19,20). Chronic stress associated with anticipated stigma may further complicate the health of PLWH by contributing to the development of co-morbid chronic illnesses such as diabetes, heart disease, and cancer (21,22).

Enacted HIV stigma may have particularly strong associations with physical indicators of health and well-being among PLWH (path E in Figure I). PLWH may experience poor health care from providers, social rejection from friends or family members, job loss from employers, and/or physical violence from others in general. Similar to anticipated stigma, enacted stigma is characterized as a stressful experience (23). When experienced frequently over time, enacted stigma also acts as a chronic stressor that may impact HIV disease progression and other health outcomes among PLWH.

### Current Study

In the current study, we aimed to examine whether HIV stigma mechanisms differentially relate to indicators of affective, behavioral, and physical health and well-being among PLWH. As depicted in Figure I, we hypothesized that internalized HIV stigma would have strongest associations with indicators of poorer affective health and well-being (i.e., helplessness regarding, acceptance of, and perceived benefits of HIV; path A) as well as associations with indicators of poorer behavioral health and well-being (i.e., antiretroviral non-adherence and longer gaps between HIV medical care visits; path B). We hypothesized that anticipated HIV stigma would also be associated with indicators of poorer behavioral health and well-being (path C) as well as indicators of poorer physical health and well-being

(i.e., CD4 count below 200 and co-morbid chronic illnesses; path D). Finally, we hypothesized that enacted stigma would be associated with indicators of poorer physical health and well-being (path E).

## METHODS

### Procedure and Participants

Data were drawn from a study of psychosocial determinants of retention in HIV medical care at a community clinic providing integrated HIV care in the Bronx, New York. The study was introduced to clients by a member of the clinic staff and interested clients met with an interviewer to determine study eligibility. Clients had to be HIV-positive, English or Spanish speaking, and 18 years or older to be eligible for the study. Given the aims of the parent study to examine retention in care, participants also had to have been diagnosed with HIV more than two years prior to their participation date. Interviews were conducted in person with a trained interviewer in a private space and lasted approximately 60 minutes. Participants were remunerated \$15 for their time. All procedures had Institutional Review Board approval. A total of 101 people participated in the study. Six participants verbally indicated difficulty with comprehension and/or reported that they did not answer items correctly to the interviewer (e.g., by answering the HIV Stigma Mechanisms items in regards to sexual orientation rather than HIV status). Per study protocol, the interviewer systematically documented all participants who indicated difficulty and these participants were trimmed from the dataset prior to starting data analyses, yielding an analytic sample of 95.

All study materials were pilot tested at the clinic to ensure participant comprehension. The interview was translated from English to Spanish and then back translated to English to ensure accuracy. During the translation process, native Spanish speakers confirmed that the interview would be comprehended by Spanish-speaking populations represented at the clinic (e.g., Puerto Rican and Dominican).

### Materials

**HIV Stigma Mechanisms**—Although many previously validated scales include items that gauge HIV stigma mechanisms, there are no existing scales that specifically measure the stigma mechanisms defined by the HIV Stigma Framework. Therefore, items for measures of internalized, anticipated, and enacted HIV stigma were adapted from previously validated scales (9,24) according to the criteria specified by Earnshaw and Chaudoir (6). Internalized HIV stigma was measured with 6 items including *“I feel ashamed of having HIV.”* Anticipated HIV stigma was measured with 9 items including *“Healthcare workers will treat me with less respect.”* Enacted HIV stigma was measured with 9 items including *“Family members have avoided me.”* Items were rated on 5-point Likert-type scales with higher scores indicating greater stigma. Items were averaged to create composite scores (internalized HIV stigma:  $\alpha = .89$ ; anticipated HIV stigma:  $\alpha = .87$ ; enacted HIV stigma:  $\alpha = .87$ ). All items are included in Appendix A.

**Affective Health and Well-Being**—The Illness Cognitions Questionnaire was used to evaluate three aspects of affective well-being: feelings of helplessness regarding, acceptance of, and perceived benefits of one’s HIV status (14). The scale, originally developed for people living with a variety of chronic illnesses, was adapted for PLWH in the current study by replacing the word *“illness”* with *“HIV.”* For example, participants were asked: *“My HIV frequently makes me feel helpless”* (helplessness subscale), *“I have learned to live with my HIV”* (acceptance subscale), and *“I have learned a great deal from my HIV”* (perceived benefits subscale). Items were rated on a 4-point Likert-type scale ranging from *not at all* to

*completely*. Each subscale included six items, and the subscales were summed to create composite scores (helplessness:  $\alpha = .82$ ; acceptance:  $\alpha = .86$ ; perceived benefits:  $\alpha = .74$ ).

**Physical Health and Well-Being**—We included two measures of physical health and well-being: chronic illness comorbidity and CD4 count less than 200. To assess chronic illness comorbidity, participants were asked whether they had been diagnosed with any of the following: asthma, diabetes, heart disease, hypertension, respiratory disease, and hepatitis C. Diabetes, heart disease, hypertension, respiratory disease, and hepatitis C have been highlighted by the HIV Medicine Association of the Infectious Diseases Society of America as chronic illness comorbidities that are particularly important to identify and treat among PLWH given their impact on HIV treatment and overall patient health (25). Asthma was identified by the clinic staff as a chronic illness comorbidity that was prevalent among the client population and impacted patient health. Participants were classified as having been diagnosed with a chronic illness (1) or never been diagnosed (0).

CD4 T lymphocytes count was abstracted from participants' electronic medical records. Given that CD4 count of less than 200 can be used to diagnosis AIDS (25) and represents significant devastation of immune system functioning, participants were classified as having a CD4 count as less than 200 (1) or greater than or equal to 200 (0).

**Behavioral Health and Well-Being**—We included two measures of behavioral health and well-being: number of days in medical care gaps and ARV treatment non-adherence. To assess number of days in medical care gaps, participants' HIV care utilization was abstracted from their electronic medical records. The HIV Medicine Association of the Infectious Diseases Society of America recommends that PLWH with normal CD4 counts and low viral loads be monitored every 3–4 months (25). Additionally, the clinic from which participants were recruited recommends that PLWH have a care visit at least once every 3 months. Therefore, participants were considered to have had a gap in care if they had not had an HIV medical visit in a 3 month period (i.e., 90 days). Each day that exceeded this period between clinic visits over the past 18 months was summed to identify the total number of days participants were poorly retained in their HIV medical care.

ARV treatment non-adherence was measured with two items evaluated in the Swiss HIV Cohort Study (26). The first item gauges adherence by asking participants how often they had missed a dose of HIV medication in the past four weeks. The second item gauges drug holidays by asking participants whether they had forgotten two doses of HIV medication in a row in the past four weeks. Participants who indicated that they never missed a dose and that they had never forgotten two doses in a row in the past four weeks were classified as adherent (0) and all others were classified as non-adherent (1) in the current study. Participants were also able to indicate that they were not currently taking HIV medication.

**Participant Demographic and HIV Characteristics**—Participants indicated their age, gender, ethnicity (i.e., Latino or non-Latino), race, whether they were born outside of the United States, sexual orientation, educational achievement, and annual income. They further indicated the number of years they had been living with HIV and whether they had engaged in medical drug treatment (e.g., buprenorphine, methadone) in the past 18 months.

## Data Analyses

First, we conducted a series of descriptive analyses to examine the sample characteristics. Second, we conducted several preliminary analyses to explore the properties of the HIV stigma mechanism measure, given that this was the first time that it had been used. We examined the reliability of the subscales using Cronbach's alpha. We also examined the



bivariate correlations between the HIV stigma mechanisms as well as the correlations between the HIV stigma mechanisms and participant characteristics. Third, we conducted a series of multivariate linear and logistic regression analyses to evaluate our hypotheses. Each regression controlled for demographic characteristics that were associated with indicators of health and well-being in preliminary bivariate analyses, as well as the effects of each HIV stigma mechanism. In this way we were able to determine which HIV stigma mechanism was associated with each indicator of health or well-being while controlling for the effects of other HIV stigma mechanisms. We excluded participants who were not currently taking HIV medication ( $n = 15$ ) from all analyses examining HIV treatment adherence.

## RESULTS

### Sample Characteristics

Characteristics of the analytic sample (Table I) generally reflect those of the clinic population from which the sample was recruited. Participants were diverse in terms of age and gender. The majority of participants identified as Latino(a) and/or Black, and heterosexual or straight. In general, participants were socioeconomically disadvantaged with 41% not having completed high school and 56% reporting an annual income under \$10,000 per year. Participants reported living with HIV for an average of 16 years, and 22% reported a history of drug treatment in the past 18 months. Although 40% of the sample had been born outside of the US, most had enough English proficiency to complete the interview in English. Therefore, only 11% elected to complete the survey in Spanish.

Levels of HIV stigma were low within this sample (Table I). Average scores indicated that participants “disagreed” that they had internalized stigma, anticipated that future experiences of stigma were “unlikely”, and reported that they had “never” or “not often” experienced enacted stigma. Average helplessness scores indicated that participants “not at all” to “somewhat” felt helpless in regards to their HIV. Average acceptance scores indicated that participants had “somewhat” or “to a large extent” accepted their HIV. Average perceived benefits scores indicated that participants perceived benefits of their HIV “to a large extent.” The majority of participants reported living with a chronic illness comorbidity. Approximately 20% had a CD4 count less than 200, meeting this criterion for AIDS diagnosis. The average number of days in medical care gaps over the past 18 months was approximately 66. Of the 80 participants who reported taking ARVs, 58% reported having missed at least one dose of medication in the past month.

### HIV Stigma Mechanism Measure

As noted in the measures description, each subscale had strong internal reliability indicated by Cronbach’s alpha ( $\alpha = .87 - .89$ ). Bivariate analyses demonstrated that internalized HIV stigma was positively correlated with anticipated HIV stigma, but was uncorrelated with enacted HIV stigma (Table II). Enacted HIV stigma and anticipated HIV stigma were positively correlated. Therefore, the three scales were considered to be distinct with the majority of variability in each scale non-overlapping (27).

Further, bivariate analyses demonstrated that completing the survey in Spanish and years living with HIV negatively correlated with internalized HIV stigma. Trends were also noted for female gender with higher and drug treatment history with lower internalized HIV stigma. Therefore, participants who completed the survey in English, participants who had been diagnosed with HIV more recently, women, and participants without a drug treatment history reported greater internalized stigma. There was a trend for gay, lesbian, or bisexual

sexual orientation to be associated with higher enacted HIV stigma. None of the evaluated demographic variables demonstrated significant correlations with anticipated HIV stigma.

### Differentiating Between HIV Stigma Mechanisms

Preliminary bivariate analyses examining the indicators of health and well-being indicated that Latino ethnicity was associated with greater helplessness ( $r = 0.20$ ,  $p = 0.06$ ); whereas Black race ( $r = -0.24$ ,  $p = 0.02$ ) and education ( $r = -0.22$ ,  $p = 0.03$ ) were associated with lower helplessness. Older age was associated with greater acceptance ( $r = 0.18$ ,  $p = 0.09$ ). Female gender was associated with greater perceived benefits ( $r = 0.19$ ,  $p = 0.07$ ); whereas completing the survey in Spanish ( $r = -0.29$ ,  $p = 0.01$ ) and having been born outside the US ( $r = -0.34$ ,  $p = 0.01$ ) were associated with lower perceived benefits. Older age ( $r = 0.25$ ,  $p = 0.01$ ) and drug treatment history ( $r = 0.22$ ,  $p = 0.03$ ) were associated with having one or more chronic illness comorbidities; whereas reporting gay, lesbian, or bisexual sexual orientation was associated with having no chronic illness comorbidities ( $r = -0.35$ ,  $p = 0.01$ ). More years living with HIV was associated with having a CD4 count lower than 200 ( $r = -0.19$ ,  $p = 0.07$ ); whereas female gender ( $r = 0.18$ ,  $p = 0.08$ ) and higher income ( $r = 0.19$ ,  $p = 0.07$ ) were associated with having a CD4 count greater than 200. Higher income was associated with having more days in medical care gaps ( $r = 0.24$ ,  $p = 0.02$ ); whereas older age ( $r = -0.40$ ,  $p = 0.01$ ) and more years living with HIV ( $r = -0.24$ ,  $p = 0.02$ ) were associated with fewer days in medical care gaps. No characteristics were associated with ARV treatment non-adherence. Multivariate regression analyses controlled for demographic characteristics correlated with the outcome (e.g., analyses examining days in medical care gaps controlled for age, income, and years living with HIV).

As hypothesized, multivariate regression analyses demonstrated that internalized HIV stigma was uniquely associated with indicators of poorer affective health and well-being, including greater helplessness, lower acceptance, and lower perceived benefits of having HIV (Table III). Internalized HIV stigma was further uniquely associated with indicators of poorer behavioral health and well-being, including more days in medical care gaps and greater likelihood of ARV non-adherence (effect marginal,  $p = 0.06$ ). Unexpectedly, internalized HIV stigma was associated with lower likelihood of having been diagnosed with a chronic illness comorbidity. As hypothesized, anticipated HIV stigma was associated with an indicator of physical health and well-being, greater likelihood of having been diagnosed with a chronic illness comorbidity. Unexpectedly, anticipated HIV stigma was marginally associated with lower likelihood of having a CD4 count less than 200 ( $p = 0.07$ ). As hypothesized, enacted HIV stigma was also associated with an indicator of physical health and well-being, greater likelihood having a CD4 count lower than 200.

## DISCUSSION

In the current study, we explored whether the HIV stigma mechanisms proposed by the HIV Stigma Framework (6) are differentially associated with indicators of health and well-being among PLWH. We explored these associations using both self-report and medical record data among a sample of PLWH currently participating in HIV treatment in the Bronx, New York. Results demonstrate that internalized HIV stigma had the strongest associations with indicators of affective health and well-being (i.e., greater helplessness regarding, lower acceptance of, and lower perceived benefits of HIV), as well as indicators of behavioral health and well-being (i.e., greater days in medical care gaps and marginal greater likelihood of ARV non-adherence). Anticipated HIV stigma was associated with an indicator of physical health and well-being (i.e., greater likelihood of chronic illness comorbidity), and enacted HIV stigma was also associated with an indicator of physical health and well-being (i.e., greater likelihood of having a CD4 count lower than 200). Taken together, we found empirical support for the majority of the hypothesized paths in Figure I, including A, B, D,

and E. Contrary to hypotheses, anticipated HIV stigma was not associated with indicators of behavioral health and well-being (path C in Figure I) and internalized HIV stigma was associated with an indicator of better physical health and well-being (i.e., lower likelihood of chronic illness comorbidity) in the current sample.

### Limitations and Future Directions

There are several inherent limitations to this study which should be considered when interpreting the results. Perhaps chief among these is the study's cross-sectional design. This limits our ability to form conclusions regarding the causal associations between HIV stigma mechanisms and health outcomes. Past research using longitudinal designs provide some support for the associations shown in this work. For example, internalized stigma is predictive of poor mental health outcomes among people diagnosed with mental illness and substance abuse (28), and enacted stigma is predictive of poor physical health outcomes among racial and ethnic minorities (29) over time. The cross-sectional design, however, may be particularly limiting for studying associations between anticipated stigma and indicators of health and well-being. Anticipated stigma gauges people's thoughts about what will happen to them in the *future*. We would expect that it would have its strongest effect on people's health behaviors in the *future*. It may have weaker associations with people's health behaviors in the *past*. This may explain why our hypothesis regarding the association between anticipated HIV stigma and behavioral health and well-being (path C in Figure I) was not supported in the current study. Future research should examine the prospective associations between all HIV stigma mechanisms and health and well-being outcomes using longitudinal methodologies to test whether HIV stigma mechanisms differentially predict health and well-being outcomes over time, and better examine whether anticipated stigma is associated with health behaviors.

We also employed a new measure of HIV stigma mechanisms. Our preliminary analyses demonstrated that this measure had strong internal consistency and measured distinct constructs. This measure further replicated associations between stigma and indicators of health and well-being found in past research (4,15,30). Therefore, we have reported some evidence in favor of the measure's reliability and validity. Future research should continue to evaluate the reliability, validity, and generalizability of this measure among larger, more diverse samples of PLWH. In particular, such future research should examine associations between this measure and other indicators of mental health and well-being such as depression, anxiety, and self-esteem, as this study focused on indicators of affective health and well-being. Future research should also examine associations with other indicators of physical health and well-being such as cancers and tuberculosis.

Additionally, we conducted this study with a sample of participants living in the Bronx, New York who were accessing medical care and experienced low levels of HIV stigma. Given the relatively high prevalence of HIV in the Bronx and the poor health experienced by this sample, it is arguably important to test these associations within this population. However, this sample is not representative of all PLWH. For example, many clients of this clinic had not graduated from high school which may explain why some participants had difficulty comprehending the questionnaire. It is important for future research to examine the generalizability of these findings by testing whether they replicate among samples representing other populations of PLWH including those who have a wider range of sociodemographic backgrounds, who are not accessing medical care, who are experiencing higher levels of HIV stigma, and who have been living with HIV for less than two years. We also tested these associations with a sample size of 95. Although a post-hoc power analysis indicated that we had sufficient power (i.e., power for all analyses exceeded .90), future research should also test these associations among larger samples of PLWH.



In the current work, we examined the main effects of the HIV stigma mechanisms on different indicators of health and well-being because we were testing whether HIV stigma mechanisms are differentially associated with such indicators. Future research may also examine ways in which the HIV stigma mechanisms relate to each other, including how the HIV stigma mechanisms develop over time. For example, preliminary work with people living with a variety of chronic illnesses suggests that people who have experienced greater enacted stigma and who have internalized greater stigma may, in turn, anticipate greater stigma (10). Thus, internalized and enacted stigma may play roles in the development of anticipated stigma, thereby indirectly influencing outcomes via anticipated stigma. Such longitudinal research may also elucidate the finding that number of years living with HIV is associated with decreased internalized HIV stigma. PLWH who seek meaning, support, and acceptance in the years post-diagnosis may experience reduced internalized HIV stigma (31). Further, interactions and associations between HIV stigma mechanisms may be important to understand. For example, PLWH who are high in both internalized and anticipated HIV stigma may engage in different health behaviors than PLWH who are high in only internalized or anticipated HIV stigma. Such research that examines all three stigma mechanisms simultaneously in multivariate analyses might also elucidate past findings on the association between enacted HIV stigma and indicators of affective health and well-being (9). It is possible that enacted HIV stigma is associated with poorer affective health under certain moderating circumstances, such as when enacted stigma is responded to with an internalizing reaction (e.g., blaming the self for the experience of discrimination). Finally, interactions between HIV stigma mechanisms and other stigma mechanisms should be explored in future research. Our preliminary analyses indicated that levels of HIV stigma mechanisms may vary among people who possess other socially devalued characteristics, including female gender; Spanish language; gay, lesbian, or bisexual sexual orientation; and drug treatment history. There is a developing body of research and theory considering intersectionality, or how other stigmas and/or characteristics may shape people's experience of HIV stigma (32,33). Future research should examine how other stigmas and characteristics intersect and ultimately shape the health outcomes of the diverse population of people living with HIV.

### **Contributions of Work: Differentiating between HIV Stigma Mechanisms**

Despite these limitations, this study advances understandings of the association between HIV stigma and health and well-being. Similar to past research (4), the current study suggests that HIV stigma has a substantial impact on health and well-being. For example, for every one point increase in internalized HIV stigma, participants had an average gap of 20 days between routine HIV medical care visits. For every one point increase in enacted stigma, participants were 343% more likely to have a CD4 count less than 200. Beyond past research, the current study suggests that HIV stigma mechanisms may be differentially associated with indicators of health and well-being. Internalized stigma may have stronger associations with affective and behavioral health and well-being, and anticipated and enacted stigma may have stronger associations with physical health and well-being.

By differentiating between HIV stigma mechanisms within research, we may be able to develop more precise tools with which to study and understand how HIV stigma relates to health and well-being among PLWH. As an example, we found that enacted HIV stigma was associated with increased likelihood of having a CD4 count below 200. We found this in multivariate analyses (OR = 4.43, CI = 1.21–16.19,  $p = 0.03$ ) as well as bivariate analyses ( $r = .22$ ,  $p = 0.03$ ). In both multivariate and bivariate analyses, neither internalized stigma (multivariate: OR = 1.35, CI = 0.64–2.86,  $p = 0.43$ ; bivariate:  $r = -0.03$ ,  $p = 0.80$ ) nor anticipated stigma (multivariate: OR = 0.39, CI = 0.14–1.07,  $p = 0.07$ ; bivariate:  $r = -0.11$ ,  $p = 0.29$ ) were associated with having a CD4 count below 200. Additionally, when we

collapsed across all HIV stigma mechanisms, the bivariate association between HIV stigma and CD4 count was non-significant ( $r = 0.01$ ,  $p = 0.98$ ). Therefore, if we had only looked at internalized stigma or anticipated stigma or if we had collapsed across stigma mechanisms, we would not have found an association between HIV stigma and having a CD4 count below 200. Thus, distinguishing between HIV stigma mechanisms may lead to the identification of associations otherwise potentially masked by not examining all stigma mechanisms or by collapsing across mechanisms.

Differentiating between HIV stigma mechanisms within research may have especially significant implications for interventions to improve health and well-being among PLWH. Although such intervention efforts have had limited success thus far, results from the current study suggest that targeting specific HIV stigma mechanisms may be effective in improving specific outcomes. For example, when intervening to improve affective and/or behavioral health and well-being, it may be particularly important to reduce internalized HIV stigma among PLWH. Given that internalized HIV stigma may result from negative feelings and beliefs held prior to HIV acquisition (7), reducing negative feelings and beliefs about HIV stigma at the structural level may reduce internalized HIV stigma among PLWH. In rural Tanzania, for example, PLWH reported decreased internalized stigma as HIV was viewed by the general public as a more “normal” and survivable disease (34). When intervening to improve physical health and well-being, it may be particularly important to reduce anticipated and enacted stigma among PLWH. The contact hypothesis suggests that facilitating social interaction between PLWH and others (e.g., healthcare providers, friends, family, co-workers) may help to reduce prejudice, stereotypes, and discrimination among others via the mechanisms of increased knowledge of HIV, reduced social anxiety regarding PLWH, and increased empathy towards PLWH (7). It is only with stronger, more nuanced understandings of HIV stigma that we will be able to break the associations between HIV stigma and indicators of poor affective, behavioral, and physical health and well-being among PLWH within interventions.

## Acknowledgments

A seed grant from the University of Connecticut Center for Health Intervention and Prevention partly funded this work. Training grants from the National Institute of Mental Health funded Earnshaw's (T32 MH020031) and Smith's (F31 MH093264) efforts. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health or the Center for Health Intervention and Prevention. The authors thank the participants, as well as HIV care providers and clinic staff for their support and contributions towards this project. Further, the authors thank Maria-Cristina Cruza-Guet for her assistance in translating the abstract to Spanish.

## References

1. Goffman, E. *Stigma: Notes on the Management of Spoiled Identity*. New York: Simon & Schuster; 1963. 1st Touchstone ed
2. Mahajan AP, Sayles JN, Patel VA, et al. Stigma in the HIV/AIDS epidemic: a review of the literature and recommendations for the way forward. *AIDS*. 2008; 22(2):S67–S79. [PubMed: 18641472]
3. Parker R, Aggleton P. HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Soc Sci Med*. 2003; 57:13–24. [PubMed: 12753813]
4. Logie C, Gadalla TM. Meta-analysis of health and demographic correlates of stigma towards people living with HIV. *AIDS Care*. 2009; 21(6):742–53. [PubMed: 19806490]
5. Deacon H. Towards a sustainable theory of health-related stigma: lessons from the HIV/AIDS literature. *J Community Appl Soc Psychol*. 2006; 16(6):418–25.
6. Earnshaw VA, Chaudoir SR. From conceptualizing to measuring HIV stigma: a review of HIV stigma mechanism measures. *AIDS Behav*. 2009; 13(6):1160–77. [PubMed: 19636699]

7. Quinn DM, Earnshaw VA. Understanding concealable stigmatized identities: the role of identity in psychological, physical, and behavioral outcomes. *Soc Issues Policy Rev.* 2011; 5(1):160–90.
8. Hatzenbuehler ML, Nolen-Hoeksema S, Erickson SJ. Minority stress predictors of HIV risk behavior, substance use, and depressive symptoms: results from a prospective study of bereaved gay men. *Health Psychol.* 2008; 27(4):455–62. [PubMed: 18643003]
9. Berger BE, Ferrans CE, Lashley FR. Measuring stigma in people with HIV: psychometric assessment of the HIV stigma scale. *Res Nurs Health.* 2001; 24(6):518–29. [PubMed: 11746080]
10. Earnshaw VA, Quinn DM. The impact of stigma in healthcare on people living with chronic illnesses. *J Health Psychol.* 2012; 17:157–68. [PubMed: 21799078]
11. Mellins CA, Kang E, Leu C-S, Havens JF, Chesney MA. Longitudinal study of mental health and psychosocial predictors of medical treatment adherence in mothers living with HIV disease. *AIDS Patient Care STDS.* 2003; 17(8):407–16. [PubMed: 13678542]
12. Safren SA, Kumarasamy N, James R, Raminani S, Solomon S, Mayer KH. ART adherence, demographic variables and CD4 outcome among HIV-positive patients on antiretroviral therapy in Chennai, India. *AIDS Care.* 2005; 17(7):853–62. [PubMed: 16120502]
13. Mak WWS, Poon CYM, Pun LYK, Cheung SF. Meta-analysis of stigma and mental health. *Soc Sci Med.* 2007; 65(2):245–61. [PubMed: 17462800]
14. Evers AWM, Kraaimaat FW, van Lankveld W, Jongen PJH, Jacobs JWJ, Bijlsma JWJ. Beyond unfavorable thinking: the Illness Cognition Questionnaire for chronic diseases. *J Consult Clin Psychol.* 2001; 69(6):1026–36. [PubMed: 11777106]
15. Sayles JN, Wong MD, Kinsler JJ, Martins D, Cunningham WE. The association of stigma with self-reported access to medical care and antiretroviral therapy adherence in persons living with HIV/AIDS. *J Gen Intern Med.* 2009; 4;24(10):1101–8.
16. Author citation removed for blind review.
17. Cole SW, Kemeny ME, Taylor SE. Social identity and physical health: accelerated HIV progression in rejection-sensitive gay men. *J Pers Soc Psychol.* 1997; 72(2):320–35. [PubMed: 9107003]
18. Link BG, Phelan JC. Stigma and its public health implications. *Lancet.* 2006; 367:528–9. [PubMed: 16473129]
19. Leserman J. HIV disease progression: depression, stress, and possible mechanisms. *Biol Psychiatry.* 2003; 54(3):295–306. [PubMed: 12893105]
20. Leserman J. Role of depression, stress, and trauma in HIV disease progression. *Psychosom Med.* 2008; 1;70(5):539–45.
21. Kiecolt-Glaser JK, McGuire L, Robles TF, Glaser RE. Emotions, morbidity, and mortality: new perspectives from psychoneuroimmunology. *Annu Rev Psychol.* 2002; 53(1):83–107. [PubMed: 11752480]
22. McEwen B. Allostasis and allostatic load implications for neuropsychopharmacology. *Neuropsychopharmacology.* 2000; 22(2):108–24. [PubMed: 10649824]
23. Williams DR, Neighbors HW, Jackson JS. Racial/ethnic discrimination and health: findings from community studies. *Am J Public Health.* 2008; 98(S1):S29–S37. [PubMed: 18687616]
24. Visser MJ, Kershaw T, Makin JD, Forsyth BWC. Development of parallel scales to measure HIV-related stigma. *AIDS Behav.* 2008; 12(5):759–71. [PubMed: 18266101]
25. Aberg JA, Kaplan JE, Libman H, et al. Primary care guidelines for the management of persons infected with Human Immunodeficiency Virus: 2009 update by the HIV medicine association of the Infectious Diseases Society of America. *Clin Infect Dis.* 2009; 49(5):651–81. [PubMed: 19640227]
26. Glass TR, De Geest S, Weber R, et al. Correlates of self-reported nonadherence to antiretroviral therapy in HIV-infected patients. *J Acquir Immune Defic Syndr.* 2006; 41(3):385–92. [PubMed: 16540942]
27. Brown, TA. Confirmatory Factor Analysis for Applied Research. New York: Guilford Press; 2006.
28. Link BG, Struening EL, Rahav M, Phelan JC, Nuttbrock L. On stigma and its consequences: evidence from a longitudinal study of men with dual diagnoses of mental illness and substance abuse. *J Health Soc Behav.* 1997; 38(2):177–90. [PubMed: 9212538]

29. Williams DR, Mohammed SA. Discrimination and racial disparities in health: evidence and needed research. *J Behav Med.* 2008; 22;32:20–47.
30. Vanable PA, Carey MP, Blair DC, Littlewood RA. Impact of HIV-related stigma on health behaviors and psychological adjustment among HIV-positive men and women. *AIDS Behav.* 2006; 8;10:473–82.
31. Alonzo AA, Reynolds NR. Stigma, HIV, and AIDS: an exploration and elaboration of a stigma trajectory. *Soc Sci Med.* 41(3):303–315. [PubMed: 7481925]
32. Earnshaw, VA.; Kalichman, SC. Stigma experienced by people living with HIV/AIDS. In: Liamputtong, P., editor. *Stigma, Discrimination, and Living with HIV/AIDS: A Cross-Cultural Perspective.* New York, NY: Springer; In press
33. Logie CH, James L, Tharao W, Loutfy MR. HIV, gender, race, sexual orientation, and sex work: A qualitative study of intersectional stigma experienced by HIV-positive women in Ontario, Canada. *PLoS Med.* 2011; 8(11):e1001124. [PubMed: 22131907]
34. Roura M, Urassa M, Busza J, Mbata D, Wringe A, Zaba B. Scaling up stigma? The effects of antiretroviral roll-out on stigma and HIV testing. Early evidence from rural Tanzania. *Sex Transm Infect.* 2009; 85:308–312. [PubMed: 19036776]

## Appendix A. HIV Stigma Mechanism Measure

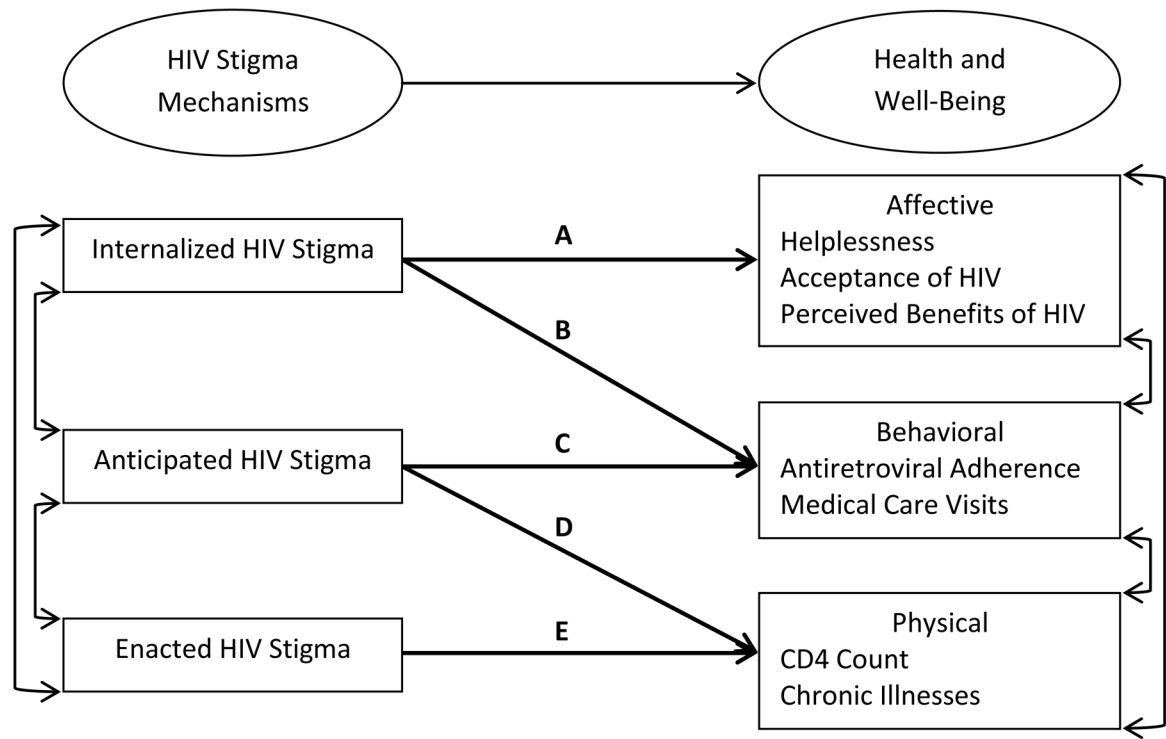
How do you feel about being HIV-positive?					
Statement	Strongly disagree	Disagree	Neither disagree nor agree	Agree	Strongly agree
1. Having HIV makes me feel like I'm a bad person.	1	2	3	4	5
2. I feel I'm not as good as others because I have HIV.	1	2	3	4	5
3. I feel ashamed of having HIV.	1	2	3	4	5
4. I think less of myself because I have HIV.	1	2	3	4	5
5. Having HIV makes me feel unclean.	1	2	3	4	5
6. Having HIV is disgusting to me.	1	2	3	4	5

How likely is it that people will treat you in the following ways in the future because of your HIV status?					
Statement	Very unlikely	Unlikely	Neither unlikely nor likely	Likely	Very Likely
1. Family members will avoid me.	1	2	3	4	5
2. Family members will look down on me.	1	2	3	4	5
3. Family members will treat me differently.	1	2	3	4	5
4. Community/social workers won't take my needs seriously.	1	2	3	4	5
5. Community/social workers will discriminate against me.	1	2	3	4	5
6. Community/social workers will deny me services.	1	2	3	4	5
7. Healthcare workers will not listen to my concerns.	1	2	3	4	5

How likely is it that people will treat you in the following ways in the future because of your HIV status?					
Statement	Very unlikely	Unlikely	Neither unlikely nor likely	Likely	Very Likely
8. Healthcare workers will avoid touching me.	1	2	3	4	5
9. Healthcare workers will treat me with less respect.	1	2	3	4	5

How often have people treated you this way in the past because of your HIV status?					
Statement	Never	Not Often	Somewhat Often	Often	Very Often
1. Family members have avoided me.	1	2	3	4	5
2. Family members have looked down on me.	1	2	3	4	5
3. Family members have treated me differently.	1	2	3	4	5
4. Community/social workers have not taken my needs seriously.	1	2	3	4	5
5. Community/social workers have discriminated against me.	1	2	3	4	5
6. Community/social workers have denied me services.	1	2	3	4	5
7. Healthcare workers have not listened to my concerns.	1	2	3	4	5
8. Healthcare workers have avoided touching me.	1	2	3	4	5
9. Healthcare workers have treated me with less respect.	1	2	3	4	5





**Figure I.**  
Hypothesized associations between HIV stigma mechanisms and health and well-being among PLWH. Paths in bold are evaluated within current paper.

**Table I**

Analytic Sample Characteristics, n = 95

Characteristic	% (n)	M (SD)
Age		49.34 (9.45)
Gender		
Female	50.5 (48)	
Male	49.5 (47)	
Ethnicity: Latino(a)	55.8 (53)	
Race		
Black	48.4 (46)	
Other: White, Multiracial, Other	49.5 (47)	
Spanish Survey	10.5 (10)	
Born Outside of US	40.0 (38)	
Sexual Orientation		
Heterosexual or Straight	78.9 (75)	
Gay, Lesbian, or Bi-sexual	21.1 (20)	
Education		
Some School	41.1 (39)	
High School Degree or More	58.9 (56)	
Annual Income		
Under \$5,000	13.7 (13)	
\$5,001 – \$10,000	42.1 (40)	
\$10,001 – \$20,000	21.1 (20)	
\$20,001 – \$30,000	9.5 (9)	
\$30,001 and Above	13.7 (13)	
Years Living with HIV		15.56 (6.50)
Drug Treatment	22.1 (21)	
HIV Stigma Mechanisms		
Internalized HIV Stigma		2.15 (0.86)
Anticipated HIV Stigma		1.93 (0.70)
Enacted HIV Stigma		1.31 (0.46)
Helplessness		10.15 (4.34)
Acceptance		18.32 (4.60)
Perceived Benefits		19.59 (4.45)
Days in Medical Care Gaps		66.28 (87.27)
ARV Non-Adherence		
Non-Adherent	48.4 (46)	
Adherent	35.8 (34)	
Not on Treatment	15.8 (15)	
Chronic Illness Comorbidity	77.9 (74)	
CD4 Count Less than 200	10.0 (19)	

**Table II**

Correlations between HIV Stigma Mechanisms and Sample Characteristics

	Internalized HIV Stigma	Anticipated HIV Stigma	Enacted HIV Stigma
HIV Stigma Mechanisms			
Internalized HIV Stigma	-		
Anticipated HIV Stigma	$r = 0.24, p = 0.02$	-	
Enacted HIV Stigma	$r = 0.11, p = 0.31$	$r = 0.35, p < 0.01$	-
Sample Characteristics			
Age	$r = -0.12, p = 0.24$	$r = -0.02, p = 0.87$	$r = -0.07, p = 0.48$
Female Gender	$r = 0.19, p = 0.07$	$r = -0.03, p = 0.79$	$r = -0.09, p = 0.36$
Latino(a) Ethnicity	$r = -0.15, p = 0.16$	$r = 0.02, p = 0.88$	$r = 0.02, p = 0.83$
Black Race	$r = -0.04, p = 0.67$	$r = -0.08, p = 0.45$	$r = -0.12, p = 0.25$
Spanish Survey	$r = -0.32, p = 0.01$	$r = -0.16, p = 0.12$	$r = 0.03, p = 0.76$
Born Outside of US	$r = -0.04, p = 0.73$	$r = -0.09, p = 0.40$	$r = -0.04, p = 0.68$
GLB Sexual Orientation	$r = -0.06, p = 0.59$	$r = -0.01, p = 0.95$	$r = 0.18, p = 0.09$
High School Education or More	$r = 0.13, p = 0.22$	$r = 0.03, p = 0.80$	$r = -0.08, p = 0.46$
Annual Income	$r = 0.03, p = 0.78$	$r = 0.07, p = 0.49$	$r = -0.03, p = 0.76$
Years Living with HIV	$r = -0.28, p = 0.01$	$r = -0.11, p = 0.30$	$r = 0.14, p = 0.19$
Drug Treatment	$r = -0.18, p = 0.08$	$r = -0.02, p = 0.82$	$r = -0.07, p = 0.94$

**Table III**  
Associations between HIV Stigma Mechanisms and Indicators of Health and Well-being

	Affective			Behavioral			Physical	
	Helplessness	Acceptance	Perceived Benefits	Days in Medical Care Gaps	ARV Non-Adherence	Chronic Illness Comorbidity	CD4 Count < 200	
Internalized HIV Stigma	$\beta = 0.45$ $B(SE) = 2.27(0.50)$ $p < 0.01$	$\beta = -0.35$ $B(SE) = -1.85(0.54)$ $p < 0.01$	$\beta = -0.31$ $B(SE) = -1.62(0.53)$ $p < 0.01$	$\beta = 0.20$ $B(SE) = 20.24(9.96)$ $p = 0.05$	OR = 1.73 <sup>†</sup> (0.97–3.08) $p = 0.07$	OR = 0.42 (0.19–0.93) $p = 0.03$	OR = 1.35 (0.64–2.86) $p = 0.43$	
Anticipated HIV Stigma	$\beta = -0.01$ $B(SE) = -0.03(0.62)$ $p = 0.97$	$\beta = 0.01$ $B(SE) = 0.06(0.71)$ $p = 0.93$	$\beta = -0.01$ $B(SE) = -0.04(0.65)$ $p = 0.95$	$\beta = -0.02$ $B(SE) = -2.73(12.73)$ $p = 0.83$	OR = 0.90 (0.44–1.84) $p = 0.78$	OR = 4.25 (1.32–13.64) $p = 0.02$	OR = 0.39 (0.14–1.07) $p = 0.07$	
Enacted HIV Stigma	$\beta = 0.16$ $B(SE) = 1.46(0.91)$ $p = 0.11$	$\beta = 0.01$ $B(SE) = 0.04(1.03)$ $p = 0.97$	$\beta = 0.08$ $B(SE) = 0.72(0.96)$ $p = 0.46$	$\beta = -0.13$ $B(SE) = -24.97(19.10)$ $p = 0.19$	OR = 1.38 (0.49–3.87) $p = 0.54$	OR = 1.58 (0.32–7.74) $p = 0.57$	OR = 4.43 (1.21–16.19) $p = 0.03$	

Note: Standardized betas and regression coefficients with standard errors included for linear regressions. Odds ratios and confidence intervals included for logistic regressions.