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Development and Psychometric Assessment of a Multidimensional Measure of Internalized HIV Stigma in a sample of HIV-positive Adults

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Abstract

There is a need for a psychometrically sound measure of the stigma experienced by diverse persons living with HIV/AIDS (PLHA). The goal of this study was to develop and evaluate a multidimensional measure of internalized HIV stigma that captures stigma related to treatment and other aspects of the disease among sociodemographically diverse PLHA. We developed a 28-item measure of internalized HIV stigma composed of four scales based on previous qualitative work. Internal consistency reliability estimates in a sample of 202 PLHA was 0.93 for the overall measure, and exceeded 0.85 for three of the four stigma scales. Items discriminated well across scales, and correlations of the scales with shame, social support, and mental health supported construct validity. This measure should prove useful to investigators examining in the role of stigma in HIV treatment and health outcomes, and evaluating interventions designed to mitigate the impacts of stigma on PLHA.

Keywords

HIV; Stigma; measure; African American; women; healthcare

INTRODUCTION

HIV stigma negatively impacts persons living with HIV/AIDS (PLHA). High perceived stigma is associated with more depressive and other HIV-related symptoms (Sowell et al., 1997; Vanable et al., 2006), lower levels of antiretroviral therapy adherence (Rintamaki et al., 2006; Stirratt et al., 2006; Vanable et al., 2006), and poor access to medical care (Kinsler et al., 2007) for PLHA. The two most commonly used measures of stigma in PLHA (Berger et al., 2001; Sowell et al., 1997) were both developed before the era of HAART. As a result, they do not adequately capture stigma and disclosure concerns that arise in the context of HIV medication use, or living with HIV as a chronic disease. Additionally, these measures do not address stigma in the health care setting, including provider attitudes toward PLHA, concerns about confidentiality of HIV status, and unwanted disclosure caused by seeking medical care. These dimensions of stigma and HIV treatment have been identified to be

highly salient to persons living with HIV (Carr and Gramling, 2004; Kinsler et al., 2007; Rintamaki et al., 2006).

The concept of stigma is complex and is rooted in the concept of deviance from the values and social norms of a community (Goffman, 1963). It follows that the perception and experience of stigma for a PLHA may differ among social groups—including by gender, race, sexual orientation, drug use, and socioeconomic status (SES) (Herek and Capitano, 1998; Herek et al., 1998; Link and Phelan et al., 2001). Therefore, it is important to develop and evaluate measures of stigma among groups whose demographics reflect the diversity of the HIV epidemic. For example, studies of women and minorities living with HIV reveal that many mothers and fathers experience stigma in the form of stereotypes and blame directed toward HIV-positive parents (Bogart et al., 2007; Murphy et al., 2006; Sandelowski and Barroso, 2003). However, the dimensions of stigma that may be experienced as a parent have been left out of measures to date. To effectively study, measure, and ultimately reduce the stigma for PLHA, it is critical to capture the full range of perceptions and experiences of the process of stigma in a given cultural context and community (Nyblade, 2006; Parker and Aggleton, 2003).

The most commonly used stigma measure for PLHA is a 40-item scale developed and tested in 1994 in a sample of almost entirely white males (Berger et al., 2001). The instrument (and various short forms) has been found to have good internal consistency reliability in African Americans (Rao et al., 2007; Wright et al., 2007) and a rural population of predominantly white men living in New England (Bunn et al., 2007). However, the development of the instrument did not include direct input from HIV-positive women and men, such as interviews or focus groups to inform item content or formal cognitive interviewing. Additionally, in both confirmatory and exploratory factor analysis the measure has been shown to lack item discrimination across scales with many items loading onto multiple scales (Berger et al., 2001; Rao et al., 2007). A measure capturing the multifaceted nature of stigma for a diverse population of PLHA can add to our understanding of the relationship between stigma and health outcomes, and assist in evaluating the effectiveness of interventions to mitigate the negative effects of stigma for PLHA.

Studies and frameworks of stigma have often drawn the distinction between “enacted” stigma, such as acts of discrimination, and “perceived” or “internalized” stigma, which captures stigma as perceived and experienced by the person being stigmatized (Jacoby, 1994; Genberg et al., 2007; Simbayi et al., 2007). In our conceptualization of the social process of stigma, internalized stigma occurs as an individual internalizes cultural norms and narratives that identify him/her as a member of a deviant group, and assumes a “spoiled identity” as described in the work of Goffman (Goffman, 1963). The goal of this study was to develop and evaluate a multidimensional measure of internalized HIV stigma that adequately captures stigma related to treatment and other aspects of HIV among sociodemographically diverse PLHA. To accomplish this goal we built on previous focus groups and interviews with PLHA and a literature review to inform the development of a 28-item measure of stigma. In this report we describe the development and psychometric properties of the new instrument in a sample of 202 HIV-positive adults in which women, racial/ethnic minorities, and people with limited income and education were represented.

METHODS

Survey Development

To identify meaningful content for a measure of internalized stigma that includes experiences of diverse PLHA, we conducted four focus groups with HIV-positive women (n=26) and three focus groups with HIV-positive men (n=22) in 2005. Fifty-four percent of

the focus group participants were female, 56% were African American, 21% were Latino/a, over 70% reported a high school education or less, and 50% reported being homeless at present or in the past.

Focus group details and results are reported elsewhere (XXX, XXXX). Qualitative analysis of the focus group transcripts identified four higher level conceptual domains of Internalized HIV stigma: (1) confronting blame and stereotypes of HIV; (2) encountering "fear of contagion;" (3) negotiating disclosure of a stigmatized role; and (4) renegotiating social relationships. We used the concepts derived from these focus groups and the peer-reviewed literature to construct a new measure of internalized HIV stigma. The items in the new measure were designed to capture the core content of the four domains from our qualitative analysis, including stigma related to HIV treatment and parenting. Whenever possible we retained the exact language participants used to convey perceptions or experiences of stigma.

A pool of 78 items were initially drafted and then pre-tested in English by the first author in ten cognitive interviews (Willis, 1994) with HIV-positive women (n=5) and men (n=5). The cognitive interviews were conducted to identify errors and test the logic, clarity, and acceptability of individual items and of the instrument as a whole. Interview participants were asked about relative ease of questions, wording of the response categories, and interpretation of specific words and phrases to determine if their meaning was the same to the respondent and the item designers. Based on the results of cognitive interviews, the measure was modified in an iterative fashion and constructed to include a series of statements describing perceptions and experiences of internalized HIV stigma followed by a 5-point categorical response scale (*none of the time, a little bit of the time, some of the time, most of the time, all of the time*). Poorly worded and ambiguous items were then eliminated, resulting in a 52-item version of the stigma measure used in the survey data collection described below. Of these 52 items, 11 items described stigma related to HIV treatment and 7 items described stigma in the context of parenting. Approximately half of the items asked participants about their own experiences and perceptions of HIV-related stigma, while the other half of the items asked about stigma experienced by HIV-positive people in general.

Survey Participants

We collected survey data from a convenience sample of HIV-positive adults over 18 years of age in January through May of 2007. We recruited participants from five community-based organizations providing outreach and social services to HIV-positive women and men, as well as from two HIV specialty clinics in a large U.S. city. Because our goal was to test the new stigma measure in a sample that included approximately equal numbers of women and men, and was diverse with respect to race/ethnicity and socio-economic status, we intentionally recruited from several sites that provide services to large numbers of HIV-positive women and minorities, many of whom have limited education and income. We also recruited participants from one site that serves primarily male clients with private insurance or Medicare. Partnering with both community organizations and clinical sites allowed us to include individuals in our study who access the health care system and those who may not. The inclusion criteria for the study were as follows: age over 18 years, HIV-positive, ability to answer questions in English, not having participated in the earlier focus groups we conducted, and ability to provide informed consent.

Participants were recruited for the study through fliers posted at community organizations and clinic sites. Organization and clinic staff also referred interested participants to the study. A trained research associate screened potential subjects, and when eligible, invited them to complete a 154-item anonymous self-administered questionnaire that included the 52-item stigma measure in a private area of the organization or clinic.

Survey Measures

The revised 52-item version of the stigma measure was administered to 202 HIV-positive adults. To measure potential demographic, medical, and psychosocial correlates of internalized HIV stigma, we also included the following measures: 1) sociodemographic characteristics including gender, age, race/ethnicity, income, education, HIV exposure category (Berry, 2002); 2) clinical data including CD4 count, viral load, history of AIDS diagnosis, and time since HIV diagnosis (Berry et al., 2002); 3) the 5-item State Shame Scale (Marschall et al., 1994) measuring general psychological shame; 4) 5-items from the Fleishman et al. social support scale (Fleishman et al., 2000); 5) a 6-item scale measuring overall access to medical care (Cunningham et al., 1999; Cunningham et al., 1995); 6) 8 individual items measuring utilization of HIV care and mental health care (Katz et al., 2001; Shapiro et al., 1999); 7) 3 individual items measuring antiretroviral therapy use and adherence (Cunningham et al., 2000); and 8) the 12-item Medical Outcomes Study Short Form (SF-12), which was used to calculate physical (PCS) and mental health composite (MCS) scores (Hays et al., 2000; Ware et al., 1996).

Data Analysis

We conducted exploratory factor analysis on the 52-item stigma scale to examine how the underlying factor structure compared with the four hypothesized domains from our prior qualitative work. We used eigenvalues greater than 1.0 from a principal components solution, and the scree plot from a principal factor solution with squared multiple correlations as communalities (Cattell, 1966) to provide an indication of the number of underlying factors. After determining the number of factors to rotate, we performed an oblique factor rotation (PROMAX) to allow for inter-factor correlations. We then eliminated 8 of the 52 items with low factor loadings (standard regression coefficients <0.30). Next we evaluated the extent to which the 46 retained items correlated more highly with their hypothesized scales (corrected for item overlap) than they did with other scales using multitrait scaling analysis (Hays and Hayashi, 1990). We eliminated 12 items with poor item discrimination, and an additional 6 items that overlapped with items having higher item-scale correlations and better item discrimination. This resulted in 28-items defining four multi-item scales suggested by the factor analysis.

The 28-item scale retained 6 of the original 11 items describing stigma in the context of HIV treatment (in domains of stereotypes, disclosure, and social relationships). This included items about stigma from medical providers (items 10, 18, 19), disclosure concerns in the HIV clinic setting (items 13, 16), unwanted disclosures resulting from physical changes (lipdystrophy/lipoatrophy) due to ART use (item 14) and the stigma of HIV as unique from the stigma of other illnesses (item 1). Additionally, 3 of the original 7 items on parenting were retained in the domain of stereotypes, including attitudes about PLHA deserving children (item 7), adopting children (item 8), and a PLHA's ability to be a good parent (item 12). The four other items from the 52-item instrument describing disclosure concerns and social relationship stigma experienced by HIV-positive parents did not demonstrate sufficient factor loading and item discrimination to be retained in the final 28-item scale.

Mean scores for the 28-item stigma scale were transformed linearly to a 0–100 range, with lower scores reflecting fewer perceptions and experiences of internalized HIV stigma, and higher scores reflecting greater levels of stigma. We calculated the mean, standard deviation, range, skewedness, and percentage of participants scoring the minimum (floor) and maximum (ceiling) for each stigma item and subscale. The overall 28-item measure was constructed as an average of the 4 scale scores rather than as an average of the 28 items individually, so as not to give greater weight to domains that have more items.

Internal consistency reliability was estimated for each of the 4 subscales and an overall scale using Cronbach's coefficient alpha (Cronbach, 1951). In addition, we evaluated item discrimination across scales, calculating the percentage of times that items in the subscale correlated significantly higher (at least two standard errors of correlation higher) with the hypothesized subscale (correcting for overlap) compared with other scales.

We used analysis of variance to evaluate if the stigma scales were associated with sociodemographic and clinical characteristics. We examined how mean stigma scale scores varied by gender (male, female, transgender), age (18–35 yrs, 36–49 yrs, 50 yrs or older), race/ethnicity (White, African American, Latino/a, other race/ethnicity), income (above or below federal poverty level), primary language (English, another language), education (less than high school, high school diploma, college diploma), relationship status (married or in a committed relationship or not), HIV risk category (MSM, heterosexual, IDU), ever diagnosed with AIDS (Yes/No), current CD4 cell count (< 200 cells/ul, > 200 cells/ul) and current antiretroviral therapy use (Yes/No).

Content and Construct Validity of Stigma Measure

Content validity assesses how well a measure represents the construct of interest (Hays et al., 2000). The methodology used in the focus groups and cognitive interview phase of this study was selected to maximize the content validity of the items developed for the measure. To assess construct validity of the instrument we examined the associations between the 28-item internalized stigma scale and constructs we expected to be correlated with stigma based on the literature and our prior work. We hypothesized that our measure of internalized stigma would be strongly and positively correlated ($r=0.5-0.7$) with feelings of shame. Shame is one psychological experience an individual may have as a result of internalized stigma, and several studies in the literature have demonstrated these constructs to be separate, but related (Cunningham et al., 2002; Duffy, 2005; Fortenberry et al., 2002). Studies of HIV-positive adults living in the US have also demonstrated that stigma is associated with poor social support and depressive symptoms (Bairan et al., 2007; Carr and Gramling, 2004; Sowell et al., 1997; Vanable et al., 2006). Thus, we hypothesized internalized stigma would also be moderately negatively correlated ($r= -0.3$ to -0.5) with social support and mental health. Finally, we are not aware of any quantitative studies directly linking stigma and physical health. We therefore hypothesized internalized stigma would be weakly correlated with physical functioning in our sample.

RESULTS

Two hundred and two HIV-positive participants completed the survey. Refusal rates ranged from 10% to 30% depending on the site of recruitment for the study. Fifty percent of the sample was female and the mean age was 43 years (range 18–76 years). Fifty-six percent of participants were African American, 28% were White, 10% were Latino/a and 6% were Asian American, Native American, or another race/ethnicity. Over half the sample reported income below federal poverty level (\$1140 per month for family of two), and 70% reported a high school education or less. Sixty-nine percent of participants identified themselves as heterosexual, 22% reported intravenous drug use (IDU) as a risk factor for HIV, and over 70% reported being currently on antiretroviral therapy. Missing rates by stigma items ranged from 0% to 3%, and none of the scales had more than 25% of items missing. The entire survey took participants 25 minutes to complete on average, with a Flesh-Kincaid reading level of grade 6.4 (Microsoft Word 2000, Redmond, WA)

Eigenvalues and the scree plot indicated four existing underlying factors. A four-factor oblique rotation demonstrated that three of the factors consisted of items representing the four hypothesized domains. Items generated from the hypothesized domain of “stereotypes”

consistently loaded on factor 1, items from the domain of “disclosure concerns” consistently loaded on factor 2, and items from the domain of “social relationships” consistently loaded on factor 3. Items generated from the fourth domain of “fear of contagion” collapsed with “social relationships,” loading on factor 3. Finally, a new (not hypothesized) domain emerged in factor 4, consisting of items related to level of personal comfort with one’s HIV diagnosis, which we refer to as “self-acceptance”. The items reflect a range of experiences of self-acceptance. “I feel ashamed to tell other people that I have HIV” reflects a low level of self acceptance, the item “My family is comfortable talking with me about HIV” suggests a level of acceptance where an individual feels comfortable with his/her diagnosis around a trusted group of people, while “I am comfortable telling anyone I know” represents the high end of the self-acceptance trajectory. The concept of self-acceptance is central to the framework of stigma we have developed and published from our previously described qualitative data.

In Table I we report the standardized regression coefficients in the four-factor oblique solution for the 28 stigma items. Standardized regression coefficients represent the individual and non-redundant contribution that each factor is making. All items loaded consistently on one factor and no items loaded >0.30 on more than one factor or subscale. Twelve items loaded on factor 1 (stereotypes), with a range of 0.50 to 0.79; five items loaded on factor 2 (disclosure concerns) with a range of 0.60 to 0.71; seven items loaded on factor 3 (social relationships) with a range of 0.46 to 0.73; and four items loaded on factor 4 (self-acceptance) with a range of 0.37 to 0.72. Items addressing the internalized stigma of HIV as a chronic illness (item 1), disclosure concerns for care seeking and HIV medications (items 13 and 14), and perceptions/experiences of stigma from health care providers (items 18, 19) all loaded more highly than any other items on their respective factors (stereotypes, disclosure concerns, social relationships). Items describing stigma in the context of parenting (items 7, 8, 12) all loaded on factor 1 (stereotypes) with standardized regression coefficients of 0.50 or greater.

Table II reports the descriptive statistics, internal consistency reliability estimates, and item discrimination rates for the internalized stigma scales. Mean scores on the four subscales ranged from 29 (social relationships) to 54 (self-acceptance), with higher scores reflecting greater internalized stigma. Standard deviations ranged from 21 (stereotypes) to 27 (disclosure concerns). Most of the scales were positively skewed (range 0.26–0.82), with the exception of self-acceptance, which was very slightly negatively skewed (–0.03). All of the subscales had participants scoring the maximum (range 1% to 7%) and the overall scale had 1% of participants with maximum scores. All subscales also had participants scoring the minimum (range 0.5%–16%), however no participants scored the minimum on all subscales to result in an overall scale score of 0. The internal consistency reliability of the overall scale was 0.93. With the exception of the self-acceptance scale ($\alpha=0.66$) all other scales had Cronbach’s alpha of 0.85 or higher. Item discrimination rates ranged from 72% (social relationships) to 100% (stereotypes), and no item correlated significantly higher with another scale than with its own in multitrait scaling analysis.

Intercorrelations among the four scales are presented in Table III. All correlations between scales were significant ($p<.01$) and ranged between 0.33 (stereotypes and self-acceptance scales) and 0.61 (stereotypes and social relationship scales).

Table IV presents correlations between the internalized stigma scale and other constructs we hypothesized would be associated with experiences and perceptions of HIV-related stigma. Consistent with our hypothesis, the overall internalized stigma scale had a strong positive correlation with the 5-item shame scale ($r = 0.58$). The correlation between shame and social relationship stigma was strongest ($r = 0.55$) and the correlation between shame and self-

acceptance was considerably weaker ($r = 0.27$). The overall internalized stigma scale was also negatively correlated with social support ($r = -0.43$), such that persons reporting greater levels of stigma experienced low levels of social support. Social support was most strongly correlated with social relationship stigma ($r = -0.40$) and its correlation with the other scales ranged from -0.27 to -0.36 . The SF-12 MCS was also significantly negatively correlated with the stigma scales (r 's ranged -0.26 to -0.44), such that those who reported greater levels of internalized stigma also reported poorer mental health. Though we hypothesized the SF-12 PCS would be weakly correlated with the stigma scales, no significant correlation was found in our sample.

Table V presents mean internalized stigma scores by sociodemographic characteristic in our sample. We found no statistically significant differences in overall scale scores by gender or age in our sample. Mean overall scores varied by race/ethnicity among respondents, with African Americans reporting significantly greater levels of stigma compared to whites for all scales except for social relationships scale. Mean overall internalized stigma scores were also significantly higher for participants who reported income below federal poverty level, speaking a primary language other than English, no or some high school education, being unmarried, being heterosexual and being diagnosed with HIV in the past 5 years. Overall scores were not significantly associated with history of IDU, history of AIDS diagnosis, current CD4 cell count, or current ART use. Although not always reflected in the overall stigma scale means, significant differences ($p \leq 0.05$ level or greater) in stigma subscales (stereotypes, disclosure concerns, social relationships, self acceptance) were observed for one or more of the following subgroup characteristics: age, gender, race, income, language, education, relationship status, sexual preference, IDU, years since HIV diagnosis, and AIDS diagnosis (Table V).

DISCUSSION

The 28-item internalized HIV stigma measure described in this paper demonstrated good internal consistency reliability and item discrimination across scales as well as showing evidence of content and construct validity in a diverse sample of PLHA. We selected items and hypothesized scales based on our previous qualitative research, including focus groups and cognitive interviews with PLHA. Our findings suggest the instrument captures multiple important domains of internalized stigma including stigma in the context of HIV treatment and stigma as it relates to parenting as a PLHA. Additionally, the measure was informed by and tested in a sample where women, persons of color and those with low education and income were well represented.

All subscales exceeded the 0.70 internal consistency reliability threshold of adequacy for group comparisons (Nunnally and Bernstein, 1994) with the exception of the self-acceptance subscale, which nearly achieved this level of reliability. The process of self-acceptance describes how a PLHA moves from the shame of living with a spoiled identity, to engagement in a process of internal change, which ultimately leads to acceptance and a redefined identity as a person living with the disease of HIV/AIDS (XXXX. XX). We retained this scale because the process of self-acceptance, and the shame that characterizes low levels of self-acceptance has been found to be central to our own work as well as to other frameworks of stigma (Carr and Friedman, 2005; English, 1971; Lekas et al., 2006; Rutledge and Abell, 2005). As we hypothesized, internalized stigma scores correlated positively with the construct of shame, and inversely with social support and mental health. Correlations between the state shame scale and the overall internalized stigma measure and subscales ranged from 0.27 (for self-acceptance scale), to 0.58 (for overall scale). Thus, the two scales share between 7% and 34% of the variance in common (square of correlations), with a considerable amount of unique variance left over to support shame and internalized

stigma as separate constructs. Stigma scores were not significantly correlated with physical functioning. These data suggest that our measure is capturing a unique construct of stigma that is related to, but different from shame, social support and mental and physical health.

We found the stigma scales to be sensitive to several sociodemographic characteristics that may intensify stigma, providing further evidence of construct validity. Theoretical work conceptualizes stigma as a social process, rooted in and perpetuated by social inequities (Castro and Farmer, 2005; Link and Phelan, 2001; Parker and Aggleton, 2003). Therefore, the experience and intensity of HIV-related stigma may be compounded or “layered” (Castro and Farmer, 2005; Nyblade, 2006; Reidpath and Chan, 2005) among groups already marginalized because of race/ethnicity, gender, socio-economic status, sexual orientation, or drug use. In our sample, PLHA reported higher overall internalized stigma scores if they were a racial/ethnic minority, had low levels of income or education, were not a native English speaker, were not in a committed relationship, were heterosexual, or had been diagnosed with HIV more recently. We did not find differences in overall stigma scores by gender as some of the literature suggests (Carr and Gramling, 2004; Lekas et al., 2006; Sandelowski et al., 2004). This may be because our measure was developed with the input of approximately equal numbers of HIV-positive women and men, and the items are sensitive to experiences and perceptions of stigma that are relevant to both genders.

Higher internalized stigma scores among heterosexuals compared to homosexual/bisexual individuals may be reflective of the different social contexts and communities that each group resides in. Historically, the gay community has been involved in activism and education regarding HIV/AIDS, and thus HIV-related stigma experiences may be somewhat diminished compared with the experiences of many in heterosexual communities who do not consider themselves at risk. Our results also suggest that the transgender population may experience greater levels of stigma in the domains of stereotypes and social relationships; however our sample size for this subgroup was not large enough to demonstrate this conclusively in the overall scale scores. IDU’s experienced greater levels of stigma in the domain of social relationships, however sample size may also have been a limitation with this variable, and further testing in larger samples of IDU’s, transgendered persons, and non-native English speakers is needed.

In comparing our internalized stigma measure with other published stigma instruments we find some similarities. The scale developed by Berger et al. also reported four higher order factors that appear to be conceptually related to our own four scales. However, many of the items in the Berger scale load on multiple factors, which indicates poor item discrimination, suggesting that the subscales that are not measuring unique and separate domains of stigma. A brief measure of HIV-related stigma developed by Sowell et al. (Sowell et al., 1997) has also been adapted for use in recent studies (Emlet, 2006; Newman et al., 2006; Wight et al., 2006). While the Sowell measure used focus groups to inform item development, the scale has not been psychometrically evaluated in samples of women or heterosexual men (Swendeman et al., 2006).

In contrast to existing measures, our scale has been developed in the era of highly active antiretroviral therapy. While a few scales exist to measure perceived stigma specifically from health care providers (Bodenlos et al., 2004; Kinsler et al., 2007; Schuster et al., 2005), other existing measures of stigma in PLHA do not include items that also address stigma in the context of HIV treatment. We found stigma in the health care setting and related to ART to be highly relevant in our formative work and the peer-reviewed literature, and we have included items in our measure that tap these concepts (items 1, 10, 13, 14, 1, 18, 19). With the exception of item 10 and item 14, all other items describing stigma and HIV treatment load higher than any other items in the measure on their respective scales. This suggests that

the items are capturing unique aspects of stigma in the context of HIV treatment within the domains of stereotypes, disclosure concerns and social relationships.

Our formative work and the literature suggest that women and heterosexual men often describe stigma in the context of being a parent (Bogart et al., 2007; Murphy et al., 2006). Therefore, we have included 3 items on this theme to maximize the relevance of the 28-item instrument to a more diverse group of PLHA (items 7, 8, 12). These 3 items all loaded >0.50 on the subscale of stereotypes, suggesting that PLHA continue to perceive stereotypes and blame associated with their disease that label them unable or unworthy of raising a family in the eyes of their community. As HIV-infection rates in the US continue to rise in women of reproductive age and heterosexually identifying men, it is important to consider how stigma may manifest for HIV-positive parents.

There were several limitations to our study, in particular due to selection bias and convenience sampling strategy. Despite our efforts to recruit a wide range of participants, the men and women who agreed to participate may differ in significant ways from those who chose not to participate. Additionally, if an individual were not seeking medical care or support services, she or he would have had limited opportunity to be recruited into the study. Thus, the sample may be biased toward people with positive experiences in HIV clinics and community organizations, and we may not have developed and tested our instrument with adequate input from the PLHA who are the most stigmatized and isolated. Additionally, our measure of internalized HIV stigma was developed and tested in a single urban location, and further testing is needed in rural populations, as well as in subgroups that were underrepresented in our sample including transgendered persons, IDUs, and non-English speakers such as Latino/a and Asian American PLHA. Finally, our sample size of 202 participants resulted in a slightly smaller number of cases per item (4 cases) than the 5 cases per item recommended for factor analysis (Bentler, 1995).

In conclusion, we describe a new 28-item measure of internalized HIV stigma that captures multiple domains of stigma including unique themes related to ART use, the health care setting, and parenting. The measure was developed and psychometrically evaluated in a diverse sample of PLHA in which women, persons of color, and those with low SES were well represented, and it demonstrated acceptable validity and internal consistency reliability. This measure should prove useful to investigators interested in capturing the multifaceted nature of stigma in diverse populations of PLHA.

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Table 1
 Four-Factors Pattern Matrix (Standardized Regression Coefficients) for 28 Final Internalized Stigma Scale Items

Items ^a	Mean Score (SD)	Factor			
		1	2	3	4
Factor 1 = Stereotypes					
1. HIV is different than other diseases like cancer because people with HIV are judged	66 (29)	0.79	0.04	0.17	0.01
2. People assume I have done something bad to get HIV	53 (32)	0.70	0.05	0.05	0.22
3. Society looks down on people who have HIV	59 (28)	0.68	0.12	0.20	0.20
4. People think that if you have HIV then you got what you deserve	43 (30)	0.68	0.03	0.01	0.18
5. People blame me for having HIV	43 (35)	0.66	0.05	0.12	0.15
6. People assume I slept around because I have HIV	54 (33)	0.62	0.08	0.01	0.22
7. People think that if you have HIV you do not deserve to have children	50 (34)	0.59	0.12	0.00	0.18
8. People are afraid to let someone with HIV adopt a child	57 (29)	0.56	0.06	0.04	0.20
9. People think I am a bad person because I have HIV	34 (32)	0.54	0.03	0.22	0.18
10. Medical providers assume people with HIV sleep around	38 (31)	0.53	0.02	0.16	0.13
11. People lose their jobs because they have HIV	46 (26)	0.53	0.24	0.08	0.22
12. People think you can't be a good parent if you have HIV	42 (31)	0.50	0.02	0.11	0.09
Factor 2 = Disclosure Concerns					
13. I am concerned if I go to the HIV clinic someone I know might see me	28 (33)	0.06	0.71	0.03	0.20
14. I am concerned if I have physical changes from the HIV medicines people will know I have HIV	33 (33)	0.06	0.71	0.13	0.03
15. I am concerned if I go to an AIDS organization someone I know might see me	30 (34)	0.04	0.70	0.06	0.25
16. I am concerned people will find out I have HIV by looking at my medical paperwork	32 (35)	0.08	0.61	0.15	0.11
17. I am concerned that if I am sick people I know will find out about my HIV	38 (35)	0.01	0.60	0.03	0.21
Factor 3 = Social Relationships					
18. Nurses and doctors treat people who have HIV as if they are	30 (30)	0.04	0.08	0.73	0.00

Items ^a	Mean Score (SD)	Factor			
		1	2	3	4
contagious					
19. Nurses and doctors dislike caring for patients with HIV	28 (28)	0.25	0.24	0.69	0.06
20. I feel abandoned by family members because I have HIV	24 (33)	0.06	0.11	0.62	0.13
21. People treat me as less than human now that I have HIV	29 (31)	0.01	0.08	0.61	0.25
22. People avoid me because I have HIV	24 (30)	0.03	0.13	0.60	0.16
23. People I am close to are afraid they will catch HIV from me	26 (32)	0.24	0.05	0.53	0.10
24. I feel like I am an outsider because I have HIV	41 (35)	0.07	0.10	0.46	0.36
Factor 4 = Self-Acceptance					
25. I feel ashamed to tell other people that I have HIV	45 (36)	0.06	0.04	0.18	0.72
26. I am comfortable telling everyone I know that I have HIV ^b	61 (35)	0.03	0.01	0.14	0.60
27. My family is comfortable talking about my HIV ^b	55 (33)	0.23	0.03	0.14	0.40
28. It is important for a person to keep HIV a secret from co-workers	56 (33)	0.18	0.09	0.11	0.37

^aResponses to each item are on a 5-point categorical response scale (none of the time, a little of the time, some of the time, most of the time, or all of the time)

^bResponse scale values reversed for scoring

Table II
Descriptive Statistics, Internal Consistency Reliability, and Item Discrimination for Internalized Stigma Subscales and Overall Scale

Domain/ Subscale	No. of Items	Mean Score ^d	Median Score ^a	SD	Skewness of Scale ^b	% Scoring Minimum	% Scoring Maximum	Internal Consistency ^c	Item Discrimination ^d
Stereotypes	12	48	45	21	0.26	0.5	2	0.91	100
Disclosure concerns	5	32	30	27	0.76	16	3	0.85	80
Social Relationships	7	29	21	24	0.82	13	1	0.89	72
Self- acceptance	4	54	56	25	-0.03	2	7	0.66	75
Overall scale	28	41	40	19	0.61	0	1	0.93	Not applicable

^aPossible range 0–100, with higher scores indicative of greater perceived and experienced stigma

^bUnbounded

^cCronbach's coefficient α

^dPercentage of time that items in the scale correlated at least two standard errors higher with the hypothesized scale compared with other scales, correcting for item overlap with scale score

Table III

Product-Moment Correlations Among Internalized Stigma Scales

Scale	1	2	3	4
1. Stereotypes	--			
2. Disclosure concerns	0.49	--		
3. Social relationships	0.61	0.56	--	
4. Self-acceptance	0.33	0.43	0.41	--
5. Overall scale	0.76	0.81	0.83	0.70

Note: Pearson product moment coefficients, $p < .01$ for all

Table IV
Product-Moment Correlations of Internalized Stigma Scales with Other Constructs

Construct	Overall Scale	Stereotypes	Disclosure Concerns	Social Relationships	Self-Acceptance
Shame	0.58**	0.50**	0.44**	0.55**	0.27**
Social support	-0.43**	-0.28**	-0.31**	-0.40**	-0.36**
Mental health ^a	-0.50**	-0.44**	-0.39**	-0.43**	-0.26*
Physical health ^a	-0.14	-0.13	-0.17	-0.12	-0.01

* p<.05;

** p<.01

^aSF-12 mental and physical health component summary scores

Table V

Internalized Stigma Scale Mean Scores by Sociodemographic Characteristics (n = 202)

Characteristics	%Sample (n)	Overall scale	Stereotypes	Disclosure concerns	Social relationships	Self-acceptance
Gender						
Male	49.5 (100)	40.4	47.4	34.2	27.2	57.4*
Female	49.0 (99)	41.7	49.8	30.2	29.7	51.4
Female transgender	1.5 (3)	58.3	72.9*	38.3	51.2**	52.1
Age						
18–35 ^a	20.0 (40)	45.5	50.5	37.0*	36.5*	58.8
36–49	54.0 (109)	40.1	47.8	29.8	26.8	54.7
50+	26.0 (53)	42.2	50.2	34.8	28.2	51.7
Race						
African American ^b	56.0 (112)	44.2*	50.7*	36.6**	30.0	58.1*
White	28.0 (56)	38.2	46.4	24.6	27.6	49.1
Latino/a	10.0 (20)	36.0	41.6	32.9	24.4	51.6
Other	6.0 (12)	46.4	54.2	40.8	33.6	52.1
Income						
Income below FPL	54.0 (109)	44.9**	51.1	37.7**	32.8**	56.7
Income above FPL	46.0 (93)	38.1	46.5	26.1	24.1	51.7
Primary language						
English	94.0 (191)	41.1*	48.1*	31.4*	28.1	54.5
Non-English	6.0 (11)	54.5	63.0	48.5	40.9	52.3
Education						
No / some high school ^c	24.0 (48)	46.2*	50.7	39.2*	36.1*	59.5*
Graduated high school	46.0 (92)	39.7	47.3	30.4	26.6	51.8
College	30.0 (60)	41.1	50.2	29.9	26.0	53.9
Relationship status						
Not married/in relationship	72.8 (147)	43.0*	49.9	33.0	30.5*	56.8*
Married/in relationship	27.2 (55)	38.4	46.4	30.6	24.2	48.0
Sexual preference						

Characteristics	%Sample (n)	Overall scale	Stereotypes	Disclosure concerns	Social relationships	Self-acceptance
Heterosexual	69.3 (140)	43.2*	50.9*	33.7	29.7	55.0
Homosexual / Bisexual	30.7 (62)	38.5	44.4	29.2	26.7	52.9
History of IDU						
Yes	22.5 (43)	43.7	47.9	34.6	36.6*	55.8
No	77.5 (148)	41.4	49.6	31.6	26.8	54.4
Years since HIV diagnosis						
0–5 yrs ^d	22.2 (43)	50.5**	56.9*	43.2**	36.6*	63.8*
6–10 yrs	26.3 (51)	42.4	49.4	32.5	30.0	55.3
>10 yrs	51.5 (100)	37.9	45.7	28.1	25.0	49.6
Ever diagnosed with AIDS						
Yes	43.4 (85)	40.9	60.1*	28.1*	27.0	50.7*
No	56.6 (111)	42.6	47.6	36.2	29.7	58.3
Current CD4 cell count						
<200 (cells/uL)	15.8 (32)	43.6	51.0	34.3	26.4	56.6
>201 (cells/uL)	84.2 (170)	41.4	48.6	31.9	28.5	54.0
Currently on ART						
Yes	71.4 (142)	40.6	47.7	31.6	27.3	53.7
No	28.6 (57)	44.8	52.0	35.0	32.4	55.9

* p<.05;

** p<.01

Note: FPL = federal poverty level, FPL for family of 2 is \$11.40 / month; IDU = Intravenous drug use; ART = antiretroviral therapy

^a Mean score for age 18–35 years compared with age 36–49 years

^b Mean score for African Americans compared with Whites

^c Mean score for no/some high school compared with graduated high school and college education

^d Mean score for 0–5 years since diagnosis compared with 10 years or more since diagnosis