



Published in final edited form as:

*AIDS Care*. 2010 November ; 22(11): 1314–1322. doi:10.1080/09540121003758481.

## Measuring HIV felt stigma: a culturally adapted scale targeting PLWHA in Puerto Rico

Julio Cesar Jimenez<sup>a,\*</sup>, Marieva Puig<sup>a</sup>, Juan Carlos Ramos<sup>a</sup>, Marangelie Morales<sup>a</sup>, Gloria Asencio<sup>a</sup>, Ana Cecilia Sala<sup>a</sup>, Eida Castro<sup>a</sup>, Carmen Vélez Santori<sup>b</sup>, Lydia Santiago<sup>b</sup>, and Carmen Zorrilla<sup>c</sup>

<sup>a</sup>Department of Psychology, Ponce School of Medicine, #388 Zona Industrial Reparada II, Ponce 00716, Puerto Rico

<sup>b</sup>Department of Public Health, University of Puerto Rico Medical Sciences Campus, Rio Piedras, Puerto Rico

<sup>c</sup>Department of Medicine, University of Puerto Rico Medical Sciences Campus, Rio Piedras, Puerto Rico

### Abstract

The objective of this study was to culturally adapt and validate a scale to measure HIV-related felt stigma in a group of People living with HIV/AIDS (PLWHA) in Puerto Rico. The researchers conducted a two-phase cross-sectional study with 216 participants (60, first phase; 156, second phase). The first phase consisted of the cultural adaptation of the scale; the second evaluated its psychometric properties. After conducting a factor analysis, a 17-item scale, the *HIV Felt-Stigma Scale (HFSS)*, resulted. Participants completed the Puerto Rico Comprehensive Center for the Study of Health Disparities Socio-demographic Questionnaire, the *HFSS*, the *Beck Depression Inventory-II*, and the *Sexual Abuse* dimension of the *History of Abuse Questionnaire*; the case managers completed the *Case Manager Stigma Guide* with subjects. The *HFSS* measures four dimensions: personalized stigma, disclosure concerns, negative self-image, and *concern with public attitudes*. The alpha and Pearson correlation coefficients (0.91 and 0.68, respectively) indicated satisfactory validity and reliability; the scale suggested adequate convergent validity. The *HFSS* is a culturally sensitive instrument that fills the existing gap in the measurement of felt stigma in Spanish-speaking PLWHA.

### Keywords

HIV Felt-Stigma Scale; felt stigma; Puerto Ricans living with HIV/AIDS; psychometric properties

### Background

Stigma has been associated with HIV since the condition's development (Herek & Glunt, 1988; Herek et al., 1998; Snyder, Omoto, & Crain, 1999). Stigma is often categorized as being either *felt/perceived* (fearing discrimination) or *enacted* (experiencing discrimination);

\*Corresponding author. [jujich@yahoo.com](mailto:jujich@yahoo.com).

Jacoby, 1994; Malcolm et al., 1998; Scrambler & Hopkins, 1986). Scrambler (1998) postulated that felt stigma is both a source of personal anguish and unhappiness and a disturbance in an individual's life. Puerto Rican research has focused on the study of enacted stigma (Norman, Abreu, Camdelaria, & Sala, 2009; Rodríguez Madera & Toro-Alfonso, 2003; Santiago Andújar, 1994; Varas-Díaz, Serrano-García, & Toro-Alfonso, 2004, 2005).

Fueled by a person's perceptions, beliefs, and emotions, felt stigma stymies measure; the lack of adequate instruments aimed at Spanish speakers further complicates the issue.

The importance of targeting instruments to a specific culture has been documented (Bravo, Canino, Rubio-Stipec & Woodbury-Fariña, 1991; Bravo, Woodbury-Fariña, Canino & Rubio-Stipec, 1993; Matías-Carrelo et al., 2003). Further, translating a given instrument into the language of the target population guarantees neither validity nor usefulness. This explains the reasoning behind the school of thought that proposes that *emic-etic* perspectives must inform the adaptation process (Brislin, 1986). An *emic* approach is used to evaluate a studied phenomenon from a within the culture under investigation; an *etic* approach is used to evaluate that phenomenon from without by comparing it with analogous phenomena found in diverse cultures. The *emic-etic* paradigm is critical to cultural adaptation.

The *HIV Stigma Scale (HSS)* from Berger, Ferrans, and Lashley (2001) was selected for cultural adaptation in this study. Berger et al. (2001) conceptualized HIV-related felt stigma as the awareness of a real or potential social disqualification, or the limitation of opportunity coupled with a negative change in one's self-perception. Berger et al. postulated that felt stigma could lead to unfavorable outcomes for people living with HIV/AIDS (PLWHA) such as low adherence to highly active antiretroviral therapy (HAART), decrease in help-seeking behaviors, and poor quality of life (Cameron, 2000; Chesney & Smith, 1999; Herek, 1999; Herek, Capitanio & Widaman, 2002; Moneyham et al., 1996; UNAIDS, 2000).

The *HSS* is a 40-item self-administered scale that measures perceived stigma in PLWHA using a fourpoint Likert scale (strongly disagree, disagree, agree, and strongly agree), with items categorized into four dimensions: personalized stigma, disclosure concerns, negative self-image, and *concerns with public attitudes*. Using the scale on US-based English-speaking Hispanics, Whites, and African Americans resulted in a 0.96 coefficient alpha and a test-retest correlation of 0.92, though with psychometric property shortcomings, such as item overlap between dimensions.

Some studies reduced the number of items in the *HSS* while maintaining internal consistency and construct validity (Bunn, Solomon, Miller & Forehand, 2007; Wright, Naar-King, Lam, Templin & Frey, 2007); others used different instruments to measure stigma with satisfactory validity and reliability (Holzemer et al., 2007; Kalichman et al., 2009). Whether accomplished by reducing items or modifying psychometric properties, none of these scales has been adapted for a Spanish-speaking Latino population. The study's objective was the cultural adaptation and validation of a scale to measure felt stigma in PLWHA in Puerto Rico (PR).

## Method

The Institutional Review Board approved both phases of this exploratory cross-sectional study (conducted from 2003 to 2008). The researchers discussed the study's purpose, aims, confidentiality, and the voluntary aspect of the different phases with each participant. After signing an informed consent, participants received a stipend (\$25/phase).

### Phase I

This cultural adaptation of Berger's *HSS* scale (2001) employed four focus groups that explored participants' feelings, opinions, and perceptions regarding felt stigma (Krueger & Casey, 2000).

**Samples**—Phase I participants comprised of two samples; all were receiving services from Ryan White agencies in southern PR. The 40 participants in the first sample were divided into four focus groups representing three different modes of HIV transmission (nine *men who have sex with men*, 12 *intravenous drug users*, and two groups of women [ $n = 19$ ] *infected by heterosexual contact*). The second sample consisted of 20 PLWHA who evaluated the grammar and editing process of the scale.

**Procedures**—A literature review by team members identified only English versions of existing Felt-Stigma scales. Broadening the review to include English instruments used with diverse populations (including Hispanics) led the team to decide to analyze, translate, and adapt Berger et al.'s 2001 scale.

The *HSS* (Berger et al., 2001) was translated into Spanish and then submitted to an independent bilingual professional for back translation (Bernard, 2006). Simultaneously, a qualified team composed of psychologists, a psychiatrist, and psychology doctoral students developed questions to guide the focus group sessions (first sample).

The researchers outlined the study objectives to the Ryan White case managers, who then referred potential participants; research assistants explained the study in detail to the volunteers prior to the first focus group meeting, participants completed the Puerto Rico Comprehensive Center for the Study of Health Disparities (PR-CCHD) Socio-demographic Questionnaire (see "Instruments"). The focus group sessions were recorded and transcribed.

The verbatims gathered from sample one's focus groups ( $n = 40$ ) were used to adapt items from Berger's scale and to develop new items. With a mind toward ensuring coherence with the dimensions postulated by Berger's scale, the researchers evaluated the information and the adjustments; further modification resulted in a 48-item, Likert-type scale (0 = strongly disagree, 1 = disagree, 2 = agree, and 3 = strongly agree).

The 48-item scale was then pilot-tested with a second sample of 20 PLWHA from the same geographical area as the first. As before, the focus group sessions were recorded and transcribed. Participant feedback led to further modifications, resulting in the *HIV Felt-Stigma Scale (HFSS)*.

## Phase II

This phase evaluated the psychometric properties of the scale, including factor analysis as well as reliability and validity analyses.

**Samples**—The first sample ( $n = 156$ ) was selected for both the factor analysis and the internal consistency analysis of the 48-item scale; members were recruited from the same clinics as in Phase I. The Socio-demographic information (Table 1) presented conforms to island-wide data (Surveillance Report, Puerto Rico Health Department, Office of Epidemiology and Research, & HIV/AIDS Surveillance Program, 2009).

The second sample (used for the reliability and convergent validity analyses of the *HFSS*) consisted of 106 PLWHA recruited from HIV clinics in northern and southern PR. For the test–retest analysis, 50 PLWHA from the same clinics completed the *HFSS*.

The third sample, 12 experienced (four plus years) Ryan White case managers, participated in the validation process by completing the *Case Manager Stigma Guide (CMSG)*.

**Procedures**—For the factor analysis, each clinic’s case manager gave participants an overview of the study, inviting their participation; research assistants provided details to those willing to take part. Clinical interviews were conducted to identify psychotic symptoms; participants presenting such symptoms were excluded and referred to a mental health professional; those fulfilling the inclusion criteria completed the *PR-CCHD Socio-demographic Questionnaire* and the *HFSS* (approximately 30 minutes).

Factor analysis identified the factor loadings and the dimensions in the adapted scale. Also, the internal consistency of the 48-item scale was examined. Items with a factor loading higher than 0.40 and an alpha level of 0.01, arranged in a single dimension, were included, corresponding to the conceptual definition of each dimension. The *HFSS* was developed using at least three items per dimension in order to avoid overlap. The scale was then submitted to reliability and convergent validity analyses.

PLWHA who fulfilled the inclusion criteria ( $n = 106$ ) were included in the reliability and validity analyses of the *HFSS* and completed the *PR-CCHD Socio-demographic Questionnaire*, the *Sexual Abuse* dimension of the *History of Abuse Questionnaire*, the *Beck Depression Inventory-II (BDI-II)*, and the *HFSS*. The session took approximately one hour; case managers completed the *CMSG* with each participant. For the post-test evaluation, the participants completed only the *HFSS*.

## Instruments

### Puerto Rico Comprehensive Center for the Study of Health Disparities (PR-CCHD) Socio-demographic Questionnaire

The *PR-CCHD* developed this instrument as part of a larger project. The 47-item questionnaire gathers information regarding Socio-demographics, lifestyle, substance use, and sexual behavior as well as any history of violence and/or abuse.

### **HIV Felt-Stigma Scale (HFSS)**

Developed for use with Spanish-speaking populations, the 17-item, self-administered *HFSS* measures perceived stigma in PLWHA using a four-point Likert scale, the *HFSS* measures four dimensions: personalized stigma, disclosure concerns, negative self-image, and *concern with public attitudes*. The *personalized stigma* dimension has five items and addresses the perceived consequences of other people knowing that the respondent has HIV. The *disclosure concerns* dimension has four items relating to withholding information, keeping one's HIV status secret, or worrying about others knowing one's HIV status. The *negative self-image* dimension is a five-item dimension related to the respondent's feelings of being unclean, inferior, or immoral as a result of having HIV. The *concern with public attitudes* dimension has three items referring to other people's attitudes or the consequences of others knowing one's HIV-positive status.

### **Beck Depression Inventory-II (BDI-II)**

This 21-question multiple-choice self-report inventory is composed of items relating to symptoms of depression (e.g., hopelessness, irritability), cognitions such as guilt or feelings of being punished, and physical symptoms (such as fatigue, weight loss, and sexual apathy) (Beck, Steer, & Brown, 1996).

### **Sexual Abuse dimension of the History of Abuse Questionnaire**

After reviewing the literature the researchers selected the *Sexual Abuse* dimension for the validity analysis. Stigma and HIV have been associated (Alonzo & Reynolds, 1995; Crawford, 1996; Herek et al., 2002; Pryor, Reeder, & Landau, 1999), as have stigma and sexual abuse, in both general (Browne & Finkelhor, 1986) and HIV populations (Chin, Wyatt, Vargas Carmona, Burnsloeb & Myers, 2004; Lynn, Pintar, Fite, Ecklund, & Stanford, 2004). The *History of Abuse Questionnaire* is a 39-item self-report retrospective measure that assesses three dimensions: (a) *physical and emotional abuse/neglect*; (b) *sexual abuse*; and (c) *domestic violence*. For this study, only the *Sexual Abuse* dimension was administered. This dimension (adapted from Wyatt, 1984) is a nine-item self-report retrospective measure in which participants indicate any forced sexual activity (touching/fondling, oral-genital activity, and/or intercourse). Reliability analysis using Cronbach's alpha coefficient was 0.91; test-retest reliability was 0.76.

### **Case Manager Stigma Guide (CMSG)**

Developed to identify stigmatized and non-stigmatized participants, the *CMSG* has 16 items and identifies the presence of behaviors, feelings, and/or thoughts stemming from real or perceived stigmatization. Six judges revised the items' instructions, content, and relevance; researchers defined the final version after analyzing the degree of agreement among the judges (interrater agreement). Internal consistency analysis done during this study revealed strong evidence of reliability (0.90).

### **Statistical analysis**

Factor analysis was conducted using the Alpha Factoring Extraction Method and the Varimax with Kaiser Normalization Rotation Method to evaluate and develop the *HFSS*.

Following this process, the scale was analyzed for internal consistency, test–retest reliability, and validity. Cronbach’s alpha statistical analysis was used to determine the reliability of the scale and its dimensions. Test–retest reliability was examined via *Pearson* correlation coefficients. These coefficients and an inter-correlation matrix were used to evaluate the convergent validity among the *HFSS*, the *Sexual Abuse* dimension of the *History of Abuse Questionnaire*, and the *CMSG*. In order to identify levels of stigmatization in PLWHA in PR, cut-off points were calculated using the mean, standard deviations, and percentiles (25, 50, and 75).

## Results

### Phase I

The cultural adaptation process of Berger’s *HSS* yielded a 48-item scale by adding 15 new items, rephrasing 10, eliminating seven, and keeping 23. Focus group participants reviewed the 48-item scale, recommending Spanish native terms and expressions (*criollismos*) for use in the final version of the *HFSS*.

### Phase II

Factor analysis results identified 17 items that had a factorial loading higher than 0.40 (Table 2). A minimum of three items per dimension were defined as the criteria for this analysis. The Varimax Orthogonal Rotation method over an Oblique Rotation was used in an attempt to maximize the dispersion of item-loading within factors. We revised the results of the Varimax rotation using Direct Oblimin rotation, which yielded similar effects, leading to the final 17-item *HFSS*.

Both reliability/validity analyses and internal consistency/test–retest reliability analyses were performed on the *HFSS*. *Pearson* correlations were performed to estimate reliability between pre- and post-administration; the alpha coefficients computed for the total scale and its dimensions exceeded 0.70, evidence of internal consistency, and, thus, reliability. Table 3 presents the comparison of the psychometric properties of the 48-item and 17-item scale. The alpha coefficient of the 17-item total-scale score (0.91) indicates that the scale measures both a single construct and a multidimensional one; the alpha coefficients of both scales were similar.

Temporal reliability, determined via test–retest correlations, demonstrated that three of the four dimensions were stable over time. The *personalized stigma*, *disclosure concerns*, and *negative self-image* dimensions had strong correlations, and total-scale scores in the test–retest correlations were similar. The *concern with public attitudes* dimension did not show a significant correlation.

Convergent validity was examined by comparing the *HFSS* with other measures: the *BDI-II*, the *Sexual Abuse* dimension of the *History of Abuse Questionnaire*, and the *Case Manager Guide*. An inter-correlation matrix was conducted to explore the quantitative representation of relationships within the scale (Table 4). The results showed significant correlations between the four dimensions and the total scale, even with independent items in every

dimension, suggesting it measures a general Felt-Stigma concept. These results provide partial evidence concerning the scale's construct validity.

For the convergent validity, the *HFSS*'s scores were compared to scores obtained in other measures assessing the same and different constructs (Table 5). Results demonstrated that, in general, the *HFSS* showed stronger correlations with all compared instruments than did the 48-item scale. The *HFSS* correlated more strongly to instruments that measure the same or associated constructs (*CMSG*, *BDI-II*). The correlation coefficients between the *CMSG* and the *HFSS* and its subscales were significant, ranging from strong to moderate, suggesting that the two instruments measure related constructs. Correlation coefficients between the *BDI-II* and the *HFSS* were moderate and significant with respect to the total Felt-Stigma score, personalized stigma, public attitudes, and negative self-image. Correlation coefficients between the *HFSS* and the *Sexual Abuse* dimension of the *History of Abuse Questionnaire* were low but significant with respect to personalized stigma, negative self-image, public attitudes, and *total felt stigma*.

### Cut-off points

The total scale and the cut-off points of the four dimensions were ascertained taking the sum of the total stigma scale and the sum of every dimension, which determined the level of HIV-related felt stigma experienced by the person. Table 6 shows the cut-off points for identifying three levels of felt stigma.

### Discussion

The study resulted in a reliable and valid culturally adapted scale that measures felt stigma in PLWHA in PR. As part of the adaptation process, the *emic-etic* conceptual model was applied. Using that model, investigators considered the cultural characteristics of PLWHA in PR from the *emic* perspective, which resulted in the modification of some items from the original scale, for example, changing *outcast* ("marginado") to *public nuisance* ("estorbo publico"). In addition, new items were developed (e.g., "Feeling that people rejected me makes me want to die"). Taking the *etic* view, the researchers kept the meanings and theoretical constructs of similar and modified items.

In addition, the *HFSS* allowed items to be categorized into specific dimensions, achieving well-defined dimensions and overcoming the overlap present in other scales (Berger et al., 2001; Bunn et al., 2007; Wright et al., 2007). The final version of the *HFSS* includes eight items taken directly (translated) from the Berger scale and seven that were modified by researchers; two new items were added. Of the seven modified items, six demonstrated strong factor loadings (above 0.65); the two new items were above 0.51, which values demonstrate that after modifying and adapting, the scale still showed strong factor loading. The results suggest that the cultural adaptation process increased the psychometric properties of the scale, according to the literature. Canino and Bravo (1999), Herrans (2000), and Matias et al. (2003) proposed that this is one important consequence of culturally adapting foreign instruments.

Analysis confirmed that the *HFSS* had the same four dimensions as the *HSS*. A comparison of the factor loadings for both instruments demonstrated that for six of the seven modified items, factor loadings were higher in the *HFSS* than those reported in the *HSS*. In the *HFSS*, loading values ranged from 0.47 to 0.85; in the *HSS*, values ranged from 0.30 to 0.77. Eight items were retained from the original *HSS*, and a comparison of loading values revealed that for five of them, values are higher in the *HFSS*, ranging from 0.45 to 0.77 in the *HFSS*, and from 0.53 to 0.73 in the *HSS*. The new items' factor loadings were 0.51 and 0.73. The *HFSS* evidenced stronger correlation coefficients in relation to its dimensions than did the *HSS*. Also, compared with Bunn et al.'s (2007) results, the correlation coefficients of the *HFSS* are usually higher. The lack of overlap among the dimensions of the *HFSS* make possible future independent analysis and its correlation with other instruments.

In summary, *HFSS* has been demonstrated to be valid and reliable. The convergent analyses showed that the *HFSS* correlates significantly with measures similarly or closely associated with stigma. It also demonstrated low but significant correlations with the *Sexual Abuse Dimension*, providing initial evidence of the association proposed by Chin et al. (2004), Lynn et al. (2004), and Browne and Finkelhor (1986) an association that should be considered for future studies. Various applications (e.g., screening tools in medical settings, additional investigations into the Felt-Stigma phenomenon) could benefit from this scale. Moreover, mental health professionals can use it to identify stigmatized individuals in order to anticipate future HIV-related mental health problems. The culturally sensitive and validated *HFSS* (tested on PLWHA in PR) fills a gap that existed in assessing felt stigma in Spanish-speaking PLWHA. The next step is to test it on other Spanish-speaking populations of PLWHA in the USA.

The limitation of this study is that participants were recruited according to availability from HIV clinics. Further studies could be considered to continue evaluating the psychometric properties of *HFSS* including other instruments that measure concepts associated with felt stigma. Besides the divergent validity can be examined.

## Acknowledgements

This study was supported by the Comprehensive Center of Health Disparities of Puerto Rico (PR-CCHD), Grant NCRR 1-U54RR019507. The authors wish to thank Ryan White agencies of Puerto Rico southern area, case manager, and staff for their collaboration during the data collection phase. Our special thanks to all the participants of this study. Also, a special thanks to Mr. Bob Richie for assisting in the manuscript's edition.

## References

- Alonzo AA, Reynolds NR. Stigma, HIV and AIDS: An exploration and elaboration of a stigma trajectory. *Social Science & Medicine*. 1995; 41:303–315. [PubMed: 7481925]
- Beck, AT.; Steer, RA.; Brown, GK. Manual for the Beck Depression Inventory-II. Psychological Corporation; San Antonio, TX: 1996.
- Berger B, Ferrans CE, Lashley F. Measuring stigma in people with HIV: Psychometric assessment of the HIV stigma scale. *Research in Nursing & Health*. 2001; 24:518–529. [PubMed: 11746080]
- Bernard, HR. Research methods in anthropology: Qualitative and quantitative approaches. AltaMira Press; Lanham, MD: 2006.



- Bravo M, Canino G, Rubio-Stipec M, Woodbury-Fariña M. A cross cultural adaptation of a psychiatric epidemiologic instrument: The diagnostic interview schedule's adaptation in Puerto Rico. *Culture, Medicine and Psychiatry*. 1991; 15:1–18.
- Bravo M, Woodbury-Fariña M, Canino G, Rubio-Stipec M. The Spanish translation and cultural adaptation of the diagnostic interview schedule for children (DISC) in Puerto Rico. *Culture, Medicine and Psychiatry*. 1993; 17:329–344.
- Brislin, RW. The wording and translation of research instruments. In: Lonner, WJ.; Berry, JW., editors. *Field methods in cross-cultural research*. Sage; Beverly Hills, CA: 1986. p. 137-164.
- Browne A, Finkelhor D. Impact of child Sexual Abuse: A review of the research. *Psychological Bulletin of American Psychological Association*. 1986; 99(1):66–77.
- Bunn JY, Solomon SE, Miller C, Forehand R. Measurement of stigma in people with HIV: A reexamination of the HIV Stigma Scale. *AIDS Education and Prevention*. 2007; 19(3):198–208. [PubMed: 17563274]
- Cameron E. The deafening silence of AIDS. *Health and Human Rights*. 2000; 5(1):7–24. [PubMed: 11154521]
- Canino, G.; Bravo, M. The translation and adaptation of diagnostic instruments for cross-cultural use. In: Shaffer, D.; Lucas, CP.; Richters, JE., editors. *Assessment in child and adolescent psychopathology*. Guilford Press; New York, NY: 1999. p. 285-298.
- Chesney MA, Smith AW. Critical delays in HIV testing and care: The potential role of stigma. *American Behavioral Scientist*. 1999; 42(7):1162–1174.
- Chin, D.; Wyatt, G.; Vargas Carmona, J.; Burnsloeb, T.; Myers, HF. Child sexual and HIV: An integrative risk reduction approach. In: Koenig, LJ.; Doll, LS.; O'leary, A.; Pequegnant, W., editors. *From child Sexual Abuse to adult sexual risk: Trauma, revictimization, intervention*. American Psychological Association; Washington, DC: 2004. p. 233-250.
- Crawford AM. Stigma associated with AIDS: A meta-analysis. *Journal of Applied Social Psychology*. 1996; 26:398–416.
- Herek GM. AIDS and stigma. *American Behavioral Scientist*. 1999; 42(7):1106–1116.
- Herek GM, Capitanio JP, Widaman KF. HIV-related stigma and knowledge in the United States: Prevalence and trends, 1991–1999. *American Journal of Public Health*. 2002; 92:371–377. [PubMed: 11867313]
- Herek GM, Glunt EK. An epidemic of stigma: Public reactions to AIDS. *American Psychologist*. 1988; 43(11):886–891. [PubMed: 3063145]
- Herek GM, Mitnick L, Burrell S, Chesney M, Devine P, Fullilove MT, Sweeney T. Workshop report: AIDS and stigma: A conceptual framework and research agenda. *AIDS Public Policy Journal*. 1998; 13(1):36–47. [PubMed: 10915271]
- Herrans, LL. *Psicología y medición: El desarrollo de pruebas psicológicas en Puerto Rico*. 2a. McGraw-Hill; México: 2000. *Psychology and assessment: The development of psychological tests in Puerto Rico* (2nd ed.)
- Holzemer WL, Uys LR, Chirwa ML, Greeff M, Makoae LN, Kohi TW, Durrheim K. Validation of the HIV/AIDS stigma instrument-PLWA (HASI-P). *AIDS Care*. 2007; 19(8):1002–1012. [PubMed: 17851997]
- Jacoby A. Felt versus enacted stigma: A concept revisited. Evidence from a study of people with epilepsy in remission. *Social Science & Medicine*. 1994; 38:269–274. [PubMed: 8140453]
- Kalichman SC, Simbayi LC, Cloete A, Mthembu PP, Mkhonta RN, Ginindza T. Measuring AIDS stigmas in people living with HIV/AIDS: The internalized AIDS related stigma scale. *AIDS Care*. 2009; 21(1):87–93. [PubMed: 19085224]
- Krueger, R.; Casey, M. *Focus groups. A practical guide for applied research*. 3rd. Sage; Thousand Oaks, CA: 2000.
- Lynn, SJ.; Pintar, J.; Fite, R.; Ecklund, K.; Stanford, J. Toward a social-narrative model of revictimization. In: Koenig, LJ.; Doll, LS.; O'leary, A.; Pequegnant, W., editors. *From child Sexual Abuse to adult sexual risk: Trauma, revictimization, intervention*. American Psychological Association; Washington, DC: 2004. p. 233-250.
- Malcolm A, Aggleton P, Bronfman M, Glavao J, Mane P, Verrall J. HIV-related stigmatization and discrimination: Its forms and contexts. *Critical Public Health*. 1998; 8:347–370.

- Matías-Carreló LE, Chávez LM, Negrón G, Canino G, Aguilar-Gaxiola S, Hoppe S. The Spanish translation and cultural adaptation of five mental health outcome measures. *Culture, Medicine, and Psychiatry*. 2003; 27:291–313.
- Moneyham L, Seals B, Demi A, Sowell R, Cohen L, Guillory J. Perceptions of stigma in women infected with HIV. *AIDS Patient Care and STDs*. 1996; 10:162–167. [PubMed: 11361616]
- Norman LR, Abreu S, Camdelaria E, Sala A. The effect of sympathy attitudes toward persons living with HIV/AIDS in Puerto Rico: A hierarchical analysis of women living in public housing. *AIDS Care*. 2009; 21(2):140–149. [PubMed: 19229682]
- Pryor JB, Reeder GD, Landau S. A social-psychological analysis of HIV-related stigma. *American Behavioral Scientist*. 1999; 42:1193–1211.
- Puerto Rico Health Department, Office of Epidemiology and Research, & HIV/AIDS Surveillance Program. *Epidemiology of the human immunodeficiency virus (HIV) in Puerto Rico*. Aug.2009
- Rodríguez Madera S, Toro-Alfonso J. The community we do not mention: Social vulnerability, high risk, and HIV/AIDS in transgender community in Puerto Rico. *Revista Puertorriqueña de Psicología*. 2003; 14:7–40.
- Santiago Andújar, LE. University of Puerto Rico; Rio Piedras, PR: 1994. *La construcción social de la estigmatización hacia las personas con el VIH/SIDA en el discurso médico oficial*. Social construction of the stigmatization toward people living with HIV/AIDS in the official medical discourse] (Unpublished doctoral dissertation)
- Scambler G. Stigma and disease: Changing paradigms. *The Lancet*. 1998; 352:1054–1055.
- Scrambler G, Hopkins A. Being epileptic, coming to terms with stigma. *Sociology of Health & Illness*. 1986; 8:26–43.
- Snyder M, Omoto AM, Crain AL. Punished for their good deeds. *American Behavioral Scientist*. 1999; 42(7):1175–1192.
- UNAIDS. UNAIDS Best Practice Collection. UNAIDS/00.16E. Author; Geneva, Switzerland: 2000. HIV and AIDS-related stigmatization, discrimination and denial: Forms, contexts and determinants.
- Varas-Díaz, N.; Serrano-García, I.; Toro-Alfonso, J. *Estigma y diferencia social: VIH/SIDA en Puerto Rico [Social difference and stigma: HIV/AIDS in Puerto Rico]*. Ediciones Huracan; San Juan, PR: 2004.
- Varas-Díaz N, Serrano-García I, Toro-Alfonso J. AIDS-related stigma and social interaction: Puerto Ricans living with HIV/AIDS. *Qualitative Health Research*. 2005; 15(2):169–187. [PubMed: 15611202]
- Wright K, Naar-King S, Lam P, Templin T, Frey M. Stigma revised: Reliability and validity of a brief measure for HIV + Youth. *Journal of Adolescent Health*. 2007; 40(1):96–98. [PubMed: 17185215]
- Wyatt, GE. *The Wyatt Sex History Questionnaire*. University of California at Los Angeles; Los Angeles, CA: 1984.

**Table 1**Sample demographics ( $n = 156$ ).

	Males	Females
Age ( $n_M = 0\ 84$ ; $n_F = 0\ 72$ )		
M	45	41
SD	8.9	8.2
Marital status ( $n_M = 0\ 84$ ; $n_F = 0\ 71$ )		
	% ( $n$ )	% ( $n$ )
Never married	35.7 (30)	18.3 (13)
Married	20.2 (17)	11.3 (8)
Cohabiting	22.6 (19)	31.0 (22)
Divorced	9.5 (8)	14.1 (10)
Separated	7.1 (6)	12.7 (9)
Widowed	4.8 (4)	12.7 (9)
Employment status ( $n_M = 0\ 82$ ; $n_F = 0\ 71$ )		
Working	23.2 (19)	14.1 (10)
Self-employed	3.7 (3)	1.4 (1)
Disabled	30.5 (25)	18.3 (13)
Unemployed	35.4 (29)	56.3 (40)
Retired	2.4 (2)	1.4 (1)
Other	4.9 (4)	8.5 (6)
Education ( $n_M = 0\ 84$ ; $n_F = 0\ 70$ )		
High school or less	59.5 (50)	74.3 (52)
Technical or vocational course	6.6 (5)	5.7 (4)
Some university	13.1 (11)	5.7 (4)
Associate degree	7.1 (6)	11.4 (8)
Baccalaureate	6.0 (5)	1.4 (1)
Graduate studies	8.3 (7)	1.4 (1)
Monthly income ( $n_M = 0\ 81$ ; $n_F = 0\ 70$ )		
Less than \$300	42.0 (34)	55.7 (39)
\$301–\$600	22.2 (18)	27.1 (19)
\$601–\$900	8.6 (7)	8.6 (6)
\$901–\$1200	9.9 (8)	2.9 (2)
\$1201 or more	17.3 (14)	5.7 (4)

Table 2

Factor analysis.

	Personalized stigma		Disclosure concerns		Negative self-image		Concern with public attitudes	
	Berger's Scale	HIV Felt-Stigma Scale	Berger's Scale	HIV Felt-Stigma Scale	Berger's Scale	HIV Felt-Stigma Scale	Berger's Scale	HIV Felt-Stigma Scale
32. I feel that people who know I am HIV + are afraid of becoming infected. <sup>a</sup>	0.69	0.85						
33. When people find out you are HIV +, they begin to look for your faults. <sup>a</sup>	0.57	0.75						
37. People who know I am HIV + say things that offend me. <sup>b</sup>		0.73						
28. Some people act as though it's my fault I have HIV. <sup>c</sup>	0.57	0.67						
35. People have told me that getting HIV is what I deserve for how I lived my life. <sup>c</sup>	0.53	0.60						
10. I feel the need to hide my HIV + status. <sup>a</sup>			0.73	0.80				
6. I will do anything to keep my HIV + status a secret. <sup>a</sup>			0.69	0.78				
4. Telling someone I have HIV is risky. <sup>c</sup>			0.65	0.73				
11. I am careful who I tell that I have HIV. <sup>c</sup>			0.73	0.70				
12. Since learning I have HIV, I feel set apart and isolated from the rest of the world. <sup>c</sup>					0.61	0.67		
24. I am embarrassed that I have HIV. <sup>a</sup>					0.30	0.65		
42. I feel like dying when others reject me. <sup>b</sup>						0.51		
13. Having HIV makes me feel that I am a pervert. <sup>a</sup>					0.77	0.47		
2. I feel guilty because I have HIV. <sup>c</sup>					0.65	0.45		

	Personalized stigma		Disclosure concerns		Negative self-image		Concern with public attitudes	
	Berger's Scale	HIV Felt-Stigma Scale	Berger's Scale	HIV Felt-Stigma Scale	Berger's Scale	HIV Felt-Stigma Scale	Berger's Scale	HIV Felt-Stigma Scale
9. Most people believe that a person who has HIV is dirty. <sup>c</sup>					0.67		0.67	0.77
8. People with HIV are treated like a public nuisance. <sup>a</sup>					0.60		0.60	0.70
15. Most people with HIV are rejected when others find out. <sup>c</sup>					0.71		0.71	0.45

Note:

*a* = modified items;

*b* = new items;

*c* = original items.

**Table 3**

Reliability coefficients for stigma dimensions and total scale.

Scale	48-item scale coefficient alpha ( <i>n</i> = 156)	17-item scale coefficient alpha ( <i>n</i> = 106)	Test-retest ( <i>n</i> =51)
HIV Felt-Stigma Scale	0.89	0.91	0.68*
Personalized stigma	0.89	0.88	0.65*
Disclosure concerns	0.86	0.85	0.73*
Negative self-image	0.76	0.77	0.70*
Concern with public attitudes	0.77	0.80	0.27

\*  
*p*<0.01.

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

**Table 4**Comparison of correlations between the *HIV Felt-Stigma Scale* and the 48-item scale.

	Personalized stigma	Disclosure concerns	Negative self-image	Concern with public attitudes
48-item scale Dimensions* ( <i>n</i> = 156)				
HIV Felt-Stigma Scale	0.76	0.66	0.74	0.58
Personalized stigma	–	0.37	0.59	0.55
Disclosure concerns		–	0.44	0.48
Negative self-image			–	0.59
Concern with public attitudes				–
17-item Felt-Stigma Scale dimensions* ( <i>n</i> = 106)				
HIV Felt-Stigma Scale	0.83	0.68	0.83	0.79
Personalized stigma	–	0.37	0.56	0.57
Disclosure concerns		–	0.44	0.40
Negative self-image			–	0.67
Concern with public attitudes				–

\* All coefficients were significant at  $p = 0.01$ .

**Table 5**

Comparison of correlations of the 48-item scale and the *HIV Felt-Stigma Scale* with the *Case Manager Stigma Guide*, the *Beck Depression Inventory*, and the *Sexual Abuse* dimension of the *History of Abuse Questionnaire*.

	Case manager guide	Beck Depression Inventory	Sexual Abuse dimension
48-item scale dimensions ( <i>n</i> = 156)			
Personalized stigma	0.36*	0.35*	0.16*
Disclosure concerns	0.45*	0.08	0.09
Negative self-image	0.34*	0.44*	0.20*
Public attitudes	0.29*	0.24*	0.12
HIV Felt-Stigma Scale	0.45*	0.35*	0.21*
17-item Felt-Stigma Scale dimensions ( <i>n</i> = 106)			
Personalized stigma	0.47*	0.37*	0.28**
Disclosure concerns	0.77**	0.10	0.15
Negative self-image	0.65**	0.44**	0.20*
Public attitudes	0.61**	0.40**	0.25**
HIV Felt-Stigma Scale	0.79**	0.39**	0.29**

\*  $p < 0.05$ ;

\*\*  $p < 0.01$ .



**Table 6**

Cut-off points.

	<b>No stigma</b>	<b>Mild</b>	<b>Moderate</b>	<b>Severe</b>
HIV Felt-Stigma Scale	0–15	16–24	25–35	>35
Personalized	0–4	5–6	7–8	9
Disclosure	0–2	3–6	7–10	>11
Negative self-image	0–6	7–9	10–11	12
Public attitudes	0–1	2–4	5–9	>10

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript