

Levels of Felt Stigma among a Group of People with HIV in Puerto Rico

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Objective: HIV felt stigma is a major problem needing to be addressed because of its association with poor treatment adherence, decreases in help-seeking behaviors, high-risk sexual conduct, emotional discomfort, and the reduction of well-being in people with HIV/AIDS (PWHA). The aim of this study was to identify the frequency of felt stigma among PWHA in Puerto Rico.

Methods: A cross-sectional study was conducted with 249 subjects (59% men, 41% women). Participants completed the Puerto Rico Comprehensive Center for HIV Disparities (PR-CCHD) Sociodemographic Questionnaire and the HIV Felt Stigma Scale.

Results: 80% of the subjects showed some level of felt stigma. Women showed significantly higher levels of HIV-related felt stigma than did men. Disclosure, negative self-image, and public attitude scores were also higher in women than in men. Sociodemographic variables such as age, marital status, employment status, income, and educational level showed significant associations with felt stigma and its dimensions.

Conclusion: Results of this study evidence the need to develop culturally sensitive intervention models to reduce the felt-stigma burden in PWHA. [*P R Health Sci J* 2012;2:64-70]

Key words: Felt stigma, HIV Felt Stigma Scale, Puerto Rican population, People with HIV/AIDS

HIV-related stigma is a complex phenomenon that has had a significant impact on people with HIV/AIDS (PLWHA) as well as on the control of the HIV/AIDS epidemic (1). During the three decades of the HIV world epidemic, a vast body of literature related to HIV stigma has been published, generating relevant information about different perspectives and the effect of the stigmatization process on the life of PWHA (2-4). The establishment of a common theoretical model of stigma has generated controversy among leading researchers (5, 6). However, many authors agree with the idea of structuring the stigma conceptual framework using two main perspectives: the interpersonal and the intrapersonal. The social or interpersonal perspective has produced fruitful knowledge about the stigmatization process and has opened routes for understanding the sociocognitive approaches of the individual dimension of stigma (3, 7, 8). On the other hand, the intrapersonal dimension of HIV-related stigma has included concepts such as felt stigma, perceived stigma, felt normative stigma, self stigma, and internalized stigma (9, 10, 7, 11, 12).

The majority of the research literature has documented the interpersonal category of HIV stigma called *enacted (social)* stigma. Enacted stigma, or social stigma, is defined as a real experience of discrimination and/or label that some individuals use to mark people who present attributes that are different from the mainstream (13, 14). In Puerto Rico and other Caribbean regions, for example, research has primarily focused on the study

of enacted stigma, particularly considering stigma from health care providers (15-18) and health care students (19) and toward HIV-positive women (20).

This paper focuses on felt stigma (also called *perceived* stigma) in PWHA in PR. Felt stigma can be characterized as feelings of fear and shame stemming from real, potential, or imaginary attitudes or discriminatory acts directed toward an HIV-positive individual and engendered by that individual's HIV status (21-24). In addition, felt stigma is associated with feelings of humiliation, guilt, fear, anger, and self-loathing (14, 25-27). Furthermore, individuals who feel stigmatized by their disease often attempt to conceal it, with the hope of protecting themselves against potential discriminatory acts (24). The following are some of the consequences of feeling stigmatized: delay in seeking medical services, poor treatment adherence, fear of disclosing HIV status (14, 28-32), reduced quality of life, and emotional distress (33). According to Scambler (34), felt

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stigma is a source of personal anguish and unhappiness and is a deep and lasting cause of worry, self-doubt, and disturbance in the life of the one who suffers it. When considering the negative repercussions of felt stigma on PWHA, several researchers have reported the existence of a number of protective factors that enable these individuals to deal with HIV stigma. These factors include social support, having been diagnosed with HIV for a long time, the absence of depressive symptoms, and having achieved a high level of education (35).

Considering the fact that what it means to be HIV positive is intricately entwined with the socialization process, the stigma experience varies across cultures (36). Thus, the complex phenomenon of felt or perceived stigma is layered by individual and sociocultural factors that influence the individual experience. In Kenya, for example, Yebei, Fortenberry, and Ayuku (37) examined, over time, changes in the experience of felt stigma in a sample of people with HIV/AIDS, attempting to determine whether these changes were dependent on sociodemographic factors. They found that living in a rural area resulted in felt stigma that persisted over time but that living in an urban was a predictor of change in the experience of felt stigma among PWHA. The team also found gender differences in terms of the presence of felt stigma, with lower levels being found in women. However, other studies from different countries and regions have found the opposite to be true, as well (38, 39). On the other hand, a study assessing internalized stigma in the US40 found no significant difference across the sample ($n = 268$) in the level of internalized stigma experienced based on age, race/ethnicity, gender, or income. The majority of HIV-positive participants in this study had experienced some level of internalized stigma related their HIV status (40). The body of literature presented here evidences the need to understand the felt-stigma phenomenon from a multidimensional perspective.

The work of Berger and colleagues has had an important impact on the understanding and measurement of the felt-stigma phenomenon among the HIV population. They postulated four sub-dimensions of felt stigma: negative self-image, disclosure concerns, concern with public attitudes, and personalized stigma (41).

Disclosure is the most studied dimension of felt stigma. It is defined as keeping one's HIV status secret or worrying about others knowing one's HIV status (41, 42). The literature has reported that the disclosure aspect is attached to the HIV-infected person's context (gender, race, social support, and social norms) (37, 43, 44). In their review article, Mayfield (45) and colleagues revealed that the disclosure of HIV-positive status is higher among women than it is among men and higher among the members of the younger Latino population than it is among the older members of this population. They also pointed out the importance of disclosure in self-identity formation. Yang (44) and colleagues found that among Chinese women, stigma was a mediator in the disposition of a woman's divulging her HIV-

positive diagnosis. Various studies have indicated that some PWHA are cautious about taking their medication in front of others, to prevent the possibility of their HIV status becoming public knowledge (46, 47). Other studies have reported some of the adverse effects of not divulging one's HIV-seropositive status, among which effects is practicing high-risk sexual behaviors that can result in the spreading of the condition throughout the community (46, 48, 49). Another sub-dimension of felt stigma is negative self-image, which is characterized by an individual's feelings of shame, dirtiness, guilt, inferiority, or immorality regarding his/her HIV condition. Past research has reported high levels of stigma and negative self-perception among the HIV population (49-51). Studies have indicated that stigmatized people experience feelings of self-hatred, self-judgment, and shame when they internalize the negative societal view toward them, thus becoming more vulnerable to expected rejection (28, 52).

Personalized stigma refers to the fear of being rejected or disqualified as a result of having HIV. Studies have suggested that the fears of being stigmatized and discriminated against are barriers to the accessing of medical services and treatment (30, 53) and HIV testing (54, 55). The last sub-dimension of felt stigma, concern with public attitudes, refers to the consequences of an individual's HIV-positive status being known by other people. One of the main challenges that HIV-positive persons deal with is the negative public reactions of others (29).

In the USA, populations considered to be disadvantaged (due to gender, race/ethnicity, sexual orientation, etc.) are more susceptible to the social inequalities that attend HIV (56-58). A meta-analysis study reported a relationship between perceived discrimination and poor health outcomes and identified mental health and physical mechanisms as pathways (59). A study from Johnson et al (60) provides evidence that treatment adherence is directly affected by stigma; the study reported on 968 PWHA who had either discontinued or never initiated antiretroviral therapy (ART). African-American participants were more likely than the participants of any other race to perceive HIV-related stigma as being an obstacle to the upholding of treatment, claiming the desire to conceal HIV status as the reason for discontinuing ART.

Currently, studies that report the prevalence of felt stigma among HIV populations are scarce; however, some have reported diverse percentages of felt-stigma prevalence. Swendman and colleagues (39) reported that 89% of participants (young drug users living with HIV/AIDS from California and New York) had experienced perceived stigma, while 51% of the participants (a group of PWHA in China) in the study undertaken by Li et al. (61) reported self-perceived stigma. The objective of the study described herein was to identify the prevalence of felt stigma and (among a group of PLWH in PR) assess its association with a number of sociodemographic variables.

Methods

Design

A cross-sectional study was conducted with a group of people with HIV in Puerto Rico. This research was conducted from 2006 to 2008.

Sample

A purposive sample of 249 HIV-positive subjects comprising 147 (59%) men and 102 (41%) women participated in this study. The participants were selected from HIV-specialized, federally funded clinics (the Puerto Rico Department of Health's Immunology Clinic, Ponce; Ryan White, Part A; Ponce Transitional Grant Area; and Iniciativa Comunitaria) using a purposive sampling strategy. Those individuals who met the following inclusion criteria were invited to participate in the study: a) able to furnish a health care provider's verification of HIV-positive serostatus, b) 21 year of age or older, c) a man or a woman without severe mental health illness, and c) able to voluntary consent.

Procedure

After the Institutional Review Board (IRB) approved this study, the researchers began the process of recruiting participants. First, the investigators informed clinical case managers of the study's objectives and inclusion criteria and asked these case managers to identify potential subjects for the study. Identified participants met with a member of the research team to discuss the study's purpose and objectives and the informed consent. This research team member conducted a screening interview using the *Brief Psychiatric Rating Scale* (BPRS) in order to ensure the absence of severe mental illness, as indicated in the inclusion criteria. The BPRS is a widely used instrument for assessing mental health status and the evolution of psychopathological symptoms. The validity and reliability of BPRS have been evaluated and accepted in many countries and languages, and its Spanish version has been accepted by Hispanic researchers (62). Three participants who presented active psychotic symptoms were referred to a mental health professional and were excluded from the study. The subjects who fulfilled the inclusion criteria completed the Puerto Rico Comprehensive Center for the Study of HIV Disparities (PR-CCHD) Sociodemographic Questionnaire and the HIV Felt-Stigma Scale (HFSS) in approximately 30 minutes. Participants received a \$25 stipend for their participation.

Instruments

PR-CCHD Sociodemographic Questionnaire

This questionnaire was developed by the PR-CCHD as part of a larger project. The 47-item questionnaire gathers information regarding sociodemographics, lifestyle, substance use, and sexual behavior, as well as any history of violence and abuse.

HIV Felt Stigma Scale (HFSS)

The HFSS is a 17-item self-administered scale developed by Jiménez and colleagues (42) to measure perceived stigma in PWHA. Participants were asked to respond to each item on a 4-point Likert-type scale, their responses indicating the degree of agreement/disagreement (0 = "strongly disagree", 1 = "disagree", 2 = "agree", 3 = "strongly agree"). The instrument has four subscales: *personalized stigma*, *disclosure concerns*, *concern with public attitudes*, and *negative self-image*. The subscale scores are computed by adding the responses of the items associated with each subscale, and a general stigma score is computed using the sum of the 17 items. General stigma scores range from 0 to 51. The Cronbach's alpha of the scale was .91, indicating good internal consistency. The reliability of the instrument, using test-retest, was .68.

Data analysis

Descriptive analyses were conducted to examine the population characteristics and the prevalence of felt stigma among PWHA in PR. In addition, Pearson's correlation and chi-square analyses were performed to explore the association of felt stigma and sociodemographic variables. All the analyses were done using the Statistical Package for Social Sciences (SPSS) version 16.0.

Results

Sociodemographic characteristics

The majority of the participants were male (59%, $n = 147$). The mean age for the total sample was 43.6 years ($SD = 9.49$), and when compared by gender, the mean age for males was slightly higher ($M_M = 45.0$, $SD = 9.45$) than it was for women ($M_F = 41.7$, $SD = 9.23$). Monthly income was \$600 or less for 72% ($n = 175$) of the participants. Employment status results reveal that 70.7% ($n = 171$) of the total sample reported being unemployed, disabled, or retired. Sixty-eight percent of the participants who reported information regarding their educational level ($n = 238$) had attained a high school education or less. Table 1 shows the sample description grouped by gender.

Felt-stigma levels

Analysis of the felt-stigma levels among these participants revealed scores ranging from 0 to 51 ($M = 22.5$; $SD = 11.4$). The analyses were grouped as proposed by Jiménez et al. (42) A score of 0-15 was categorized as *no stigma*, 16-24 was categorized as *mild stigma*, 25-35 was categorized as *moderate stigma*, and 36 or higher was categorized as *severe stigma*. The results showed that 80% of the participants had suffered from mild to *severe stigma*, thus demonstrating high levels of felt stigma. Analyses by dimensions also showed a high prevalence among these participants. *Public attitudes stigma* was present in 78.2% of the total sample, followed by *personalized stigma* (73.9%), *negative self-image* (70.3%), and *disclosure concerns* (60.6%). Table 2 shows the percentage of felt stigma for the total sample grouped by gender.

Table 1. Sociodemographic characteristics of the sample (n = 249)

Demographics	Males % (n)	Females % (n)
Marital Status (n _M = 146; n _F = 100)		
Never married	38.4 (56)	19.0 (19)
Married	11.0 (16)	11.0 (11)
Cohabiting	24.7 (36)	27.0 (27)
Divorced	12.3 (18)	18.0 (18)
Separated	10.3 (15)	15.0 (15)
Widowed	3.4 (5)	10.0 (10)
Employment Status (n _M = 142; n _F = 99)		
Working	18.3 (26)	15.2 (15)
Self-employed	8.5 (12)	1.0 (1)
Disabled	28.9 (41)	20.2 (20)
Unemployed	36.6 (52)	54.5 (54)
Retired	3.5 (5)	1.0 (1)
Other	4.2 (6)	8.1 (8)
Education (n _M = 140; n _F = 98)		
High school or less	65.0 (62)	72.4 (71)
Technical or vocational course	4.3 (6)	4.1 (4)
Some university	15.7 (22)	13.3 (13)
Associate degree	5.0 (7)	6.1 (6)
Baccalaureate	5.0 (7)	3.1 (3)
Graduate studies	5.0 (7)	1.0 (1)
Monthly income (n _M = 145; n _F = 98)		
\$300 or less	51.0 (74)	56.1 (55)
\$301 - \$600	15.2 (22)	24.5 (24)
\$601 - \$900	16.6 (24)	8.2 (8)
\$901 - \$1,200	7.6 (11)	5.1 (5)
\$1,201 or more	9.7 (14)	6.1 (6)

Table 2. Dimensions of felt stigma in the surveyed sample

Dimensions	Females %	Males %
HIV Felt Stigma*		
No Stigma	16.7	22.4
Mild Stigma	34.3	42.9
Moderate Stigma	30.4	27.2
Severe Stigma	18.6	7.5
Personalized Stigma		
No Stigma	24.5	27.2
Mild Stigma	33.3	36.1
Moderate Stigma	22.5	20.4
Severe Stigma	19.6	16.3
Disclosure Concerns*		
No Stigma	32.4	44.2
Mild Stigma	22.5	25.2
Moderate Stigma	23.5	14.3
Severe Stigma	21.6	16.3
Negative Self-image*		
No Stigma	23.5	34.0
Mild Stigma	29.4	34.0
Moderate Stigma	19.6	25.9
Severe Stigma	27.5	6.1
Public Attitudes*		
No Stigma	16.8	25.2
Mild Stigma	24.8	33.3
Moderate Stigma	46.5	35.4
Severe Stigma	11.9	6.1

*p<.05

Sociodemographic variables associated with felt stigma

A two-way contingency analysis was conducted to examine the relationship between the participants' genders and total felt stigma levels and between gender and the four dimensions of felt stigma (no stigma and mild, moderate, and severe stigma). An independent sample *t*-test conducted to examine the difference in total felt-stigma score according to the participants' genders yielded significant results: $t(247) = -2.53$. Participants' genders and total felt-stigma levels were found to be significantly related: Pearson $\chi^2(3, n = 249) = 8.54, p < .05$. Eighty-three percent of the women reported experiencing any level of felt stigma (from mild to severe) and 78% of men reported experiencing any level of felt stigma. When analyzed by severity, more women than men reported experiencing severe levels of felt stigma (19% vs. 7.5%, respectively) (Table 2). In the analysis of those with moderate to severe levels of felt stigma, 49% of the women reported a higher frequency than did men (35%). In general, total HIV felt stigma was found to be significantly associated with participants' genders, since women demonstrated higher levels of stigma than did men.

The analysis of the separate dimensions, *disclosure concerns* ($r_s [n = 249] = .14, p < .05$), *negative self-image* ($r_s [n = 249] = .20, p < .05$), and *public attitudes* ($r_s [n = 249] = .17, p < .05$) showed significant associations with participants' genders, and in all comparisons, stigma was more frequent in women (Table 2). The *disclosure concerns* dimension was present in 67.6% of women contrasted with 55.8% in men. The comparisons for *negative self-image* ($F = 76.5\%$; $M = 66\%$) and for stigma associated with *public attitudes* ($F = 83.2\%$; $M = 74.8\%$) showed the same tendency.

Age was significantly associated with two of the felt-stigma dimensions (Table 3): *disclosure concerns* ($r_s [n = 248] = -.128, p < .05$) and *negative self-image* ($r_s [n = 249] = -.147, p < .05$). Severe levels of both disclosure concerns and negative self-image were more frequently reported among participants who were in the group whose members ranged in age from 21-40 years (43.9% for *disclosure concern*, 41.1% for *negative self-image*) and those who were in the 61-70 years age group (27.3% for *disclosure concern*, 18.2% for *negative self-image*) (Table 3).

The marital status of the participants was also analyzed by examining its relationship to felt stigma levels, and only *disclosure concerns* was found to be significant, Pearson $\chi^2(15, n = 246) = 26.5, p < .05$. For this dimension, severe stigma levels were more frequent among widowed participants (26.7%), followed by those who reported that they were cohabitating (25.0%) and those who reported being divorced (19.4%) (Table 3).

Employment status, educational level, and monthly income categories were also analyzed to examine their relationships to total felt stigma and dimension levels (Table 3). Employment status was significantly associated only with *personalized stigma* ($r_s [n = 242] = .166, p < .05$). However, the correlation coefficient

for this variable was low. Unemployment was the most frequently reported status (n = 103) and of these unemployed participants, 50.5% (n = 52) reported moderate to severe levels of the total felt-stigma.

When analyzed by educational level, *disclosure concerns* ($r_s [n = 238] = .24, p < .05$) showed significant association. The majority of the participants reported having completed high school (n = 106), and among these, 29.3% (n = 31) showed moderate to severe levels of total felt stigma (Table 3).

Monthly income showed a significant relationship with *personalized stigma* ($r_s [n = 243] = -.175, p < .05$), *disclosure concerns* ($r_s [n = 243] = .159, p < .05$), and *negative self-image* ($r_s [n = 243] = -.159, p < .05$). Fifty-three percent (n = 129) of the participants reported a monthly income of \$300 or less, and of those, 45.8% (n = 59) reported moderate to severe *personalized stigma*, 31.8% (n = 41), showed moderate to severe *disclosure concerns*, and 44.2% (n = 57) reported moderate to severe *negative self-image* (Table 3).

Table 3. Sociodemographic variables associated with felt stigma

Variable	Felt Stigma				
	HFSS	Personalized	Disclosure Concerns	Negative Self-image	Public Attitudes
Gender	.166*	.054	.137*	.223*	.167*
Marital Status	.067	.067	.022	.091	.121
Employment	.058	.166*	.096	.019	.038
Education	.028	-.082	.254*	-.055	.113
Income	-.087	-.175*	.159*	-.159*	-.001
Age	-.122	-.083	-.128*	-.147*	.035

*p<.05

Discussion

The aim of this study was to measure the levels of felt stigma in a group of Puerto Ricans living with HIV and assess the association with a group of sociodemographic variables. The findings of the current study documented the frequency of felt stigma in a group of PWHA in Puerto Rico as being 80%. Previous studies reported a felt-stigma prevalence range of 51% to 89% in PWHA among young Americans and Chinese adults, respectively (39, 61). In comparison with the study of Li and colleagues, (61) our results reported lower levels in the negative self-image, while documenting higher levels of disclosure.

On the other hand, several studies have associated sociodemographic variables such as gender, educational level, income, and age with stigma (2, 44, 63, 64). Our results show that most of the individuals in the sample had a high school education, and among these participants, a high percent reported feeling stigmatized, particularly in the felt-stigma dimension of disclosure. Consonant with our findings, some studies have reported that a higher educational level is associated with low perceived HIV stigma (32, 35). In

agreement with the results herein, other studies have reported that younger people tend to divulge HIV status more frequently than do older ones (45, 31, 65, 66). The results reported in this investigation are comparable with the findings of other studies, (35, 61) in which the authors documented the association of high levels of perceived stigma with economic hardship.

In terms of the gender variable, the data are contradictory: some studies have documented higher levels of stigma in women than have been reported in men (61); others have reported the opposite (45). These results could be attributed to different factors, one such being cultural context. This study reported that more women than men expressed feeling stigmatized, specifically in the felt-stigma dimensions of disclosure, negative self-image, and concern with public attitudes.

Considering the significant impact of felt stigma on the control of the HIV epidemic and its high levels among the participants of this study, it is important to have a broader comprehension of this phenomenon and its repercussions on PWHA. Therefore, future intervention models aimed at reducing felt stigma are necessary to improve the quality of life and well-being of PWHA. Another relevant factor to acknowledge in the development of an intervention model is the specific sociocultural context and gender of a given HIV-infected individual. The felt-stigma dimension should be taken into account to reduce the spread of HIV.

The limitations of this study should be considered. For example, participants were recruited from community-based organizations and clinics (purposive sampling), thus limiting the possibility of generalizing the findings. Larger stratified epidemiological studies should be conducted on the island in order to determine whether the associations found in this study persist.

For this study, participants were recruited from community-based organizations and clinics, mainly those in the southern Puerto Rico region; a smaller sample came from Puerto Rico's northern, metropolitan area. It is important to determine whether this finding can be replicated or will differ in the other geographical regions of the island (west, east). We consider that exploring levels of felt stigma in different geographic areas will provide valuable information about these different regions' cultural influences on the experience of felt stigma as reported in the study conducted by Yebey, Fortenberry, and Ayuku (37).

The present study did not assess how long participants had been diagnosed as being HIV positive. Although the study's findings showed a high frequency of mild to severe levels of felt stigma (80%) among participants, future studies on the island should consider comparing the levels of felt stigma of newly diagnosed individuals and those of people diagnosed with HIV for a long period of time. Other studies have reported contradictory findings in terms of the relationship between the number of years diagnosed with HIV and the experience of felt

stigma (67, 68). Also, it is important to conduct longitudinal studies with newly diagnosed HIV patients, looking at the HIV felt-stigma trajectory, as conceptualized by Alonzo and Reynolds, (69) in order to provide insight on the phenomenon's evolution as experienced by the Puerto Rican population and inform targeted intervention models.

A clear direction for future research oriented by the results of this study might be an examination of the association among levels of felt stigma and its dimensions according to the mode of HIV transmission. The literature has reported how the HIV felt-stigmatization process might potentiate previous experiences of rejection caused by an individual's being a member of a marginalized or "at risk" group such as one composed of men who have sex with men, injection drug users, or commercial sex workers (69, 70).

Resumen

Objetivo: El estigma sentido en VIH es un problema mayor debido a su asociación con pobre adherencia al tratamiento, menor búsqueda de ayuda, conducta sexual riesgosa, malestar emocional y reducción del bienestar en personas con VIH/SIDA (PVS). El objetivo de este estudio fue identificar la frecuencia del estigma sentido en un grupo de PVS en Puerto Rico. **Métodos:** Se condujo un estudio transversal, con 249 sujetos (59% varones, 41% féminas). Los participantes completaron el Cuestionario Sociodemográfico del Puerto Rico Comprehensive Center for HIV Disparities (PR-CCHD) y la Escala de Estigma Sentido para personas con VIH. **Resultados:** El 80% de los participantes mostró algún grado de estigma sentido. Las mujeres mostraron niveles significativamente más altos de estigma sentido comparado con los hombres. Las puntuaciones en las escalas de revelación del diagnóstico, autoimagen negativa y actitudes públicas fueron mayores en las mujeres. **Conclusión:** Los resultados del estudio evidencian la necesidad de desarrollar modelos de intervención culturalmente sensibles dirigidos a reducir el impacto del estigma sentido en PVS.

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