

HIV-related felt stigma among Puerto Ricans living with HIV/AIDS: A focus group study

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Abstract

Stigma negatively impacts the wellbeing of people living with HIV/AIDS (PLWHA). Feeling stigmatized is known to affect key areas of daily lives of PLWHA. This study characterizes the experience of perceived stigma among a group of Puerto Ricans LWHA, through a focus group (FG) approach. A total of 40 participants were recruited from Ryan White agencies at the southern area of Puerto Rico. A qualitative study was performed to gather data concerning participants' feelings, opinions, and perceptions. The FG were audio recorded and transcribed into a written report. Content analysis was performed and the topics were coded for inter-rater reliability. The topics derived were related to: stigma experiences of rejection, emotional reactions, disclosure, reactions of others, PLWHA coping, physical appearance, and affective relationships.

Keywords: HIV/AIDS-related felt stigma, Puerto Ricans LWHA, focus group

VIH stigma percibido entre los puertorriqueños que viven con VIH/SIDA: Un estudio de enfoque de grupo

Resumen

El estigma afecta negativamente el bienestar de personas que viven con VIH/ SIDA (PLWHA). Sentirse estigmatizado afecta áreas clave de la vida cotidiana de estas personas. Este estudio caracteriza la experiencia del estigma sentido entre un grupo de puertorriqueños LWHA, a través de un enfoque de grupo focal (GF). Un total de 40 participantes fueron reclutados de las agencias de Ryan White en el área sur de Puerto Rico. Se llevó a cabo un estudio cualitativo para recopilar datos sobre los sentimientos, opiniones y percepciones de los participantes. Los GF se grabaron y transcribieron en un informe escrito. Los temas derivados del análisis de contenido se relacionaron con: rechazo, reacciones emocionales, revelación del diagnóstico, reacciones de otros, destrezas de afrontamiento, apariencia física y relaciones afectivas.

Palabras clave: VIH/ SIDA relacionados con el estigma sentido, puertorriqueños LWHA, grupos focales

Stigma phenomenon has been categorized by literature in two dimensions, felt and enacted. Enacted stigma is defined as the real experiences of rejection and discrimination. On the other hand, felt stigma, refers to a stigmatized person's internal sense of shame and fear of real or imagined societal attitudes and potential discrimination arising from a particular attribute, disease or association with a particular group

(Jacoby, 1994; Malcolm, Aggleton, Bronfman, Galvao, Mane, & Verall, 1998; Scambler, 1998; Scambler, & Hopkins, 1986; Herek, 2002). Besides, individuals who felt stigmatized by their disease attempted to conceal it, hoping to protect themselves against possible discriminatory behaviors (Scambler & Hopkins, 1986). This study is centralized in the understanding of the felt stigma concept from the perspective of people living with HIV/AIDS (PLWHA) in the island.

Felt stigma could threaten the physical and psychological well-being of PLWHA (Herek, 2002). Furthermore, felt stigma may decrease the intention

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for disclosing the condition of PLWHA, leading to a reduction in social support, increasing the HIV high risk behaviors and spreading it through the community (Chesney, & Smith, 1999; Rao, Pryor, Gaddist, & Mayer, 2008; Simabayi, Kalichman, Strebel, Cloete, Henda, & Mqeketo, 2007; Swendeman, Rotheram-Borus, Comulada, Weiss, & Ramos, 2006; Wenger, Kusseling, Beck, & Shapiro, 1994). For example, an individual may deny his/her HIV risk and decline the use of condoms. Some of the consequences of feeling stigmatized, as literature reported, are: delay in seeking medical services, poor treatment adherence, (Chesney & Smith, 1999; Herek & Glunt, 1988; Herek, et al., 1998; Kinsler et al., 2007; Link, & Phelan, 2001; Brouard, & Willis, 2006), deficient quality of life and psychological distress (Lee, Kochman, & Sikkema, 2002). Scambler (1989) proposed that felt-stigma is a source of personal anguish and unhappiness and, in its own right, a deep and lasting cause of worry, self-doubt and disturbance in the person's lives.

A conceptual model of felt stigma in PLWHA developed by Berger, Estwing, and Lashley (2001) identified four factors of felt stigma: fear of being rejected or disqualified for having HIV (personalized stigma), fear of others knowing about one's HIV status (disclosure concern), feelings of personal devaluation, guilt, and shame because of HIV (negative self-image), and perceptions of how others may think or treat someone with HIV (concerns with public attitudes). This conceptualization, suggests that felt stigma may induce a series of responses, such as change in self concept, emotional reactions towards those who stigmatize, use of avoidance or minimization strategies (e.g. information control, withdrawal, and tension reduction), challenges to stigmatization, and redefined worldview and/or priorities.

According to Herek et al., (2005) the socially marginalized individuals faced additional stigmatization described as "*symbolic AIDS stigma*". This concept involves a synergy between the stigma attached to HIV/AIDS as a disease and the stigma attached to the groups automatically associated with HIV/AIDS. Nevertheless, despite its evident negative impact on PLWHA, research on felt stigma is scarce, particularly in Hispanic/Latino populations.

In Puerto Rico, publications of stigma in PLWHA focused primarily on enacted HIV stigma. Researchers, for instance, have studied the impact social stigma has on the relationships of PLWHA with friends, family, coworkers, sexual partners and health professionals, as well as stigma experienced by PLWHA with health care professionals (Varas, Serrano, and Toro, 2005; Ruiz, Cintrón, & Varas, 2007).

Considering the impact that felt stigma has demon-

strated to have on the quality of life of PLWHA and the lack of existing research on this topic in Puerto Rico, it is important to understand the variable of stigma more profoundly. Although other efforts have been made to study enacted stigma, at the moment undergo this study, the authors did not find any investigations which focused on felt stigma on PLWHA in Puerto Rico.

The goal of this study was to explore the felt stigma experiences from the perspectives of persons living with HIV/AIDS in Puerto Rico. This study fills a gap in felt stigma research among this population on the island.

Method

Design

A qualitative study was performed using a focus groups approach to gather information concerning the participants' feelings, opinions, and perceptions, in relation to HIV stigma. Four focus groups of 8 to 11 persons living with HIV/AIDS were conducted, following the criteria established by Krueger and Casey (2000) from March, 2004 to March, 2005. The discussions were held at a drug rehabilitation residential center and two health clinics located in the southern area of Puerto Rico.

Participant screening and recruitment

The screening and recruitment of PLWHA was accomplished in collaboration with case managers from Ryan White Agencies, following the protocol accepted by the Institutional Review Board (IRB) at Ponce School of Medicine. The case managers described the nature of the study to possible participants and informed that those selected to participate in a focus group would receive a stipend for their participation in the study.

The criteria used for individual's recruitment to participate in the focus groups were the following: able to consent, 21 years of age or older, HIV positive persons, individuals free of any psychotic symptoms and willing to participate in focus groups activities.

Description of the participants

The study included four groups composed by forty persons living with HIV/AIDS and the groups were divided by gender. Groups were comprised by nine (9) men who have sex with men, twelve (12) intravenous drug users (IDU) and nineteen (19) women HIV infected through sexual intercourse. The distribution of the population was 52.5% men and 47.5% women.

The mean age in years for men was 34.5 and 39.5 for women. Most of the male participants reported a single status and less than half reported less than high

school education. Besides, more than half of the women reported a single civil status and had, at least, a high

school education. Most participants lived in urban areas. (See Table 1)

Table 1: *Sociodemographic data of the population*

	N	%	N	%	N	%
	Men		Women		Total	
Age (years)						
21 - 29	9	(43)	1	(5)	10	(25)
30 - 39	11	(52)	9	(47)	20	(50)
40 - 49	1	(5)	9	(47)	10	(25)
Marital Status						
Single	14	(67)	11	(58)	25	(63)
Married	2	(9)	1	(5)	3	(8)
Separated	0	(0)	1	(5)	1	(3)
Divorced	4	(19)	2	(11)	6	(15)
Widowed	0	(0)	3	(16)	3	(8)
Other	1	(5)	1	(5)	2	(5)
Educational Level						
Elementary School	11	(52)	3	(16)	14	(35)
Intermediate School	1	(5)	3	(16)	4	(10)
High School	1	(5)	6	(32)	7	(18)
Undergraduate studies	3	(14)	1	(5)	4	(10)
Residence Zone						
Urban	20	(95)	11	(58)	31	(78)

Procedure

The team in charge of conducting the focus groups was integrated by Clinical Psychology doctoral students, Psychologists and a Psychiatrist. This group participated in training sessions provided by one of the project's consultants, a specialist in focus group research. The topics discussed in the focus group were: stigma concept, rejection experiences, emotional reactions, and concerns with HIV diagnosis disclosure.

The focus group meetings were conducted in the participants' native language, Spanish; each was guided by a trained moderator and an assistant. The sessions took place in private rooms with seating arrangements that allowed the participants to maintain eye contact with the facilitators. Meetings lasted from 90 to 100 minutes.

At the beginning of the session, the moderator described the purpose of the study, the participants' rights and the entailed activities. All the participants' comments and questions were addressed. Thereafter,

they read and signed the consent form. To maintain anonymity, each participant chose a name by which he/she was to be identified during the discussion. Finally, participants were invited to talk about any unexplored topics they considered pertinent. Participants received a \$25.00 stipend for their attendance.

The focus groups meetings were audio recorded then transcribed for future analysis. In addition, a research assistant made annotations concerning participants' comments, nonverbal expressions, emotional reactions (e.g., crying, laughing), silences, facial expressions, and actions (e.g., hitting the table).

Data interpretation

The audio recordings of the focus groups were transcribed into written text and carefully analyzed and coded according to the established thematic framework. Two investigators from the research team independently coded and analyzed the material to

evaluate inter-rate reliability. Divergence opinions were discussed and resolved. This process was followed by analyzing the entire transcription leading emergent topics which were not originally established within our framework. This last information was included in the general comments. In addition, an external investigator, experienced in conducting qualitative research, reviewed the analysis process.

The content analysis was completed according to the discussed topics by the research team (Berg, 2007). Concept and categories were organized using a thematic framework (Ritchie & O'Connor, 2003). The study's objectives, guide questions and literature on felt stigma directed the selection of themes. A codification system was established using the theoretical framework designed by researchers.

For each topic, the researchers identified recurring themes and selected quotations to be included in the text to support it. Emphasis was given to the identification of any experiences, cultural expressions, or symbols that may point to a Puerto Rican standpoint of HIV-related felt stigma.

Findings

This study reported the PLWHA perceptions of concept and experiences related to stigma.

Definition of stigma. Stigma was defined as rejection or fear of rejection by most of the participants. Likewise, it was associated with ignorance, prejudice, discrimination, and fear. Some participants considered that the manifestations of stigma varied among different regions in the island. Many participants identified stigma with been *stamped*, or *marked*. Others utilized metaphors to define it:

"... rejection still exists; fear exists because sometimes, as a human being, if you go to meet someone and you consider that maybe this could be your partner and you say, look, I have HIV, they leave."

"...because they put a stamp on you and that stamp marks you forever."

"...about the rejection and stigma here in the south area... I lived twelve years in the metropolitan area and people are more conscious and more educated about the treatments and about what HIV is. But here in the south, I always told my mother, when I used to come to visit, not to hospitalize me here at Ponce (town at the southern area of PR.) Because I can see it already."

Experiences of Rejection. The participants stated that experiences of rejection were very frequent. They reported that the majority of these experiences had

come from healthcare providers, especially nurses and physicians. Some of the participants, nurses themselves, indicated that the nurses' attitudes of rejection toward these patients persisted, even after receiving training for HIV. The participants shared being rejected by their family members. Some attributed their attitudes to ignorance about the HIV condition. Others reported experiences of exclusion had been related to the way some friends or acquaintances have treated them. Other stigmatization experiences reflected their community members' attitudes of rejection and isolation. The participants considered the elimination of health care services for HIV patients as a sign of the government's rejection also.

"In the 80's when HIV/AIDS issue started, the fear was more than the rejection. Now in 2004, orientation has been given in many ways; television, newspapers, magazines, etc. But to this day, in 2004, rejection still exists."

"... it was a total rejection with the family. My nephews used to eat in my house and now they do not eat if not in plastics. Nobody visits me. My mother seldom comes to my house and I seldom go there. "

"To say that you have HIV, they isolate you. I had fights at the health care program; we are like back in the 80's. Being professionals, they reject you. The doctor stopped taking care of me; they didn't even draw my blood. They gave me an injection and sent me home."

Emotional reactions to experienced stigmatization. The participants expressed that feeling rejected has caused them pain and rage. They also reported feelings of frustration and irritability, as well as loss of self-esteem. Some participants describe feeling hate toward other persons and despise toward themselves.

"Rejection makes me feel so much anger...And it hurts..." "I have felt anger, frustration, rage."

"Rejection; feeling it lowers your self-esteem".

"I had it very bad, I was very sad. It feels horrible when one is rejected."

Disclosure the diagnosis. Several members of the group conveyed resistance and distrust with respect to the revelation of their diagnosis, fearing it would be known and anticipating others' rejection and discrimination. Some members of the group mentioned not having told their relatives about their condition to avoid harming them, making them suffer, or causing them pain or sorrow.

"That I had to shut up about it and unfortunately you can't find a person you could tell about your condition and there are only a few people

who would keep it a secret, because it spreads like gun powder. I have a great friend that had to leave Puerto Rico because of that, like my brother, it spread like gun powder."

"I have friends that do not dare to write HIV/SIDA (in medical forms) because of fear of being rejected by the doctor who will be seeing them or the nurse who could be treating them. That happens. That happened one time with a Doctor O. My friend did not dare to write down he had the condition for fear that nobody would want to touch him and I told him: "so your mind is weak". There is no awareness from the patients themselves, because of the fear of rejection, of prejudice."

"She (his mother) is seventy years old, she is an asthmatic person and has a lot of illnesses; I am not going to give her that suffering. May God give her many years. I, as a son, prefer to keep it to myself to not make her suffer."

Reactions of others to the disclosure. The reactions of significant people were more relevant for this group. Most of the participants perceived the rejection and distance of others when they were informed about their diagnosis. Others have reacted to their revelation with disbelief and dismissive attitudes. However, some participants reported that their families responded with unconditional support.

"I was with my cousin in the hospital, he was more than a cousin, but when I told him about my diagnosis he has diarrhea for three days. I said, if that is him, my cousin, if I tell my family, they'll die."

"They have reacted in a horrendous manner. You can notice the differences. It can be noticed in your acquaintances, I had a lot of friends before and now I don't see them."

"When I told them (her children) the first one told me: "so what" and kissed me. The girl called me a liar..."

Coping with Other People's Reactions. Some participants manifested how the needed resilience to overcome society's rejection must come from reaching the acceptance of one's self, as a person living with HIV. This group conveyed how getting educated and educating others about HIV/AIDS have helped them to constructively cope with their felt stigma. One of the participants shared that when he anticipates the possibility of being rejected he avoids it by giving false information. Getting specialized assistance has facilitated some participants in coping with stigmatizing experiences. Others point out that strengthening

relationships with their partners and families, has made rejection easier to cope with.

"Learning not to reject ourselves, preparing yourself for your condition, that someone who does not understand the condition could get information, not to isolate themselves, not to believe you will get others sick, we are locking ourselves up, we are the best guides, the best way to deal with the rejection is to work with our own self."

"Education, information to guide others, to confront aggressions, situations or people, even having AIDS, I am a human being, who has feelings. Who I think doesn't accept me, doesn't count."

"They asked me how I got infected and I lied. I have lived in many Latin-American countries and I said it was in Colombia where they injected me in an assault. So things changed. How this world is... it is a shame. If I get to say that it was sexually transmitted, they would push me away."

"I knew to fight and get ahead and look for psychological help. And my husband is terrific; he has helped me get ahead. No matter what they say, go ahead."

Opinions concerning PLWHA before their own diagnosis. The members of the group recognized that they had a negative concept concerning PLWHA and showed a predisposition to reject them. They saw the disease as a synonym of imminent death.

"I also rejected AIDS patients."

"I thought they would die fast. That stigma against AIDS is equal to death."

"Before I knew I had AIDS, for me people with AIDS were the worst, people from the streets."

Emerging Themes. The following topics were derived from the focus group discussion.

Physical appearance. The issue of weight loss, physical lesions, and signs of physical deterioration was strongly related to the risk of being identified and stigmatized as having HIV. The prejudice against HIV population instills stigmatizing behaviors.

"People notice your physical appearance; mostly they don't even want to talk to you and less of your problem."

"If you are fat, you pass, but if you are thin, ah! that one has AIDS. Then, there is a struggle inside the patient so one always stays like, well, not too skinny, nor too fat."

Consequences of rejection experiences. The experiences of rejection had a strong impact on the

participants' health-related behaviors. Most of them agreed that people's rejection has caused them to isolate from their friends and families and that it has a negative effect concerning help-seeking and adherence to treatment.

"But look, I have a friend... and I always found things for him, and I opened a record for him to get treatment. He did not want to go, because he would be seen; right now he is buried, because he died."

"When they go to the physicians' office, when they ask what conditions you have; I have friends who do not put HIV/AIDS because they fear the doctor who is going to see them would reject them or the nurse who would attend them. That happens. That happened once with a Doctor O. The friend did not dare to notify he had the condition for fear that they would not want to touch him and I told him, "then your mind is weak", there is no awareness from the patients because the fear of rejection, of prejudice."

"I believe that yes, in a way these worries and fears (refer to rejection) interfered with our treatment, out therapies. I thought one of the angles of this will impact treatment adherence."

Affective relationships. For some participants, the fear provoked by the possibility of being rejected was enough cause to leave and avoid establishing affectionate relationships as well as to increase high risk behaviors.

"I thought of the rejection they would have, then, I left the house, I thought I was going to die, I turned to drugs... the fear of rejection, what I did to myself was a terrible harm, the stigma that I caused myself, I destroyed myself."

Discussion

Almost three decades after the advent of the HIV infection and despite the substantial advances in its treatment, the stigma related to this condition continues. This phenomenon has been studied from social and perceived perspectives. Specifically, felt stigma is a complex and challenging variable to measure, due to its abstract nature and strong relation to feelings and emotions. For that reason, this study was designed to have a better understanding of felt-stigma phenomenon, through the experiences reported by a group of PLWHA in PR.

The information gathered from the participants' show that felt stigma is perceived as a frequent experience and a complex construct with negative sequelae among the targeted population. Our findings are congruent

with the results reported by Alonzo and Reynolds (1995), which documented that stigma is a multifactor concept that impacts the quality of life of PLWH. In addition, other studies reported high levels of felt stigma among American and Chinese populations, respectively (Swendeman et al., 2006; Li, Wang, Williams, & He, 2009). The participants' discourse of this study transpires that feeling stigmatized has a multidimensional impact. Its repercussions can be seen on self concept, family life, affectionate relationships, emotional well being, behaviors and treatment adherence. Some studies also reported several of these adverse effects of feeling stigmatized (Lee et al., 2002, Rao, Kekwaletswe, Hosek, Martinez & Rodriguez, 2007; Sayles, Ryan, Silver, Sarkisian & Cunningham, 2007; Vanable, Carey, Blair & Littlewood, 2006).

The participants who have felt stigmatized define it as rejection. Stigma was also connected to discrimination, prejudice, ignorance, and fear. These results are consonant with the ones reported by Letamo (2003) in which HIV/AIDS stigma have been connected to fear, ignorance and discrimination to people that live with the illness. Stigma was perceived as an irreversible, durable, and even lifelong devaluating "mark". The metaphors used by the participants were all scolding terms such as "being rotten", "having the monster" and "having the dog", suggesting a deep impact on the self.

Studies indicated that some urban groups of PLWHA disclose their sexual behavior more easily than rural ones (CDC, 1995). Besides, infected people exhibited higher levels of stigma in rural areas than in urban ones (Smith, 1997). According to the results reported previously, our participants stated that stigma differs from one region of the island to another. Participants perceived less stigmatizing attitudes in the metropolitan area than in the rest of the island. Smaller and more traditional towns were associated with more prejudiced and exclusionary attitudes.

On the other hand, some studies reported that medical health professionals treat persons with HIV/AIDS illness in a different way or refused to attend them (Damrosch, Abbey, Warner & Guy, 1990; Martin and Bedimo, 2000; Zukoski & Thorburn, 2009). Most participants perceived stigmatizing attitudes from health providers specially nurses and physicians. Several of the participants believe that even though health care providers have received training on HIV, this has not brought a significant change in how PLWHA are treated. The participants believe that stigmatizing attitudes are not just a result of lack of exposure to information about the disease.

Furthermore, many of the participants of this study felt the rejection of their families and described it as a painful stigmatization experience. Congruent with our results, another study reported less support from the family members (Lee et al., 2002).

According to this group, anybody who reveals their HIV diagnosis is at risk of being stigmatized, isolated and distanced from others. Besides, it has been an obstacle for the establishment and maintenance of affectionate relationships. In agreement with our findings, some studies reported that persons did not disclose their HIV status and isolated themselves for the fear to be stigmatized and rejected from the loved ones (Bennett et al., 1990; Kumar et al., 2006; Lee et al., 2002; Zukoski et al., 2009).

Participants highlighted that people who physically do not appear to be infected with HIV experience less rejection. Consonant with our results, Bennett (1990) pointed out that individuals conceal with their symptoms and lesions related to the HIV/AIDS condition to avoid being discriminated.

According to some participants living with HIV, stigma generates a series of unpleasant emotions such as hate, anger, sadness, frustration, pain, loneliness, isolation, and rage. For some, these feelings instill a negative self perception. This negative view of the self is characterized by self hate, feelings of worthlessness, lack of self care, isolation, loss, hopelessness, and self-destructive behaviors. Other researches indicated also emotions such as anger among HIV/AIDS population (Bennett, 1990; Lee et al., 2002, Zukoski et al., 2009).

Some participants conveyed that, in order to cope with society's stigmatization, one must accept and assert oneself. They considered important educating themselves and others in relation to the HIV/AIDS illness and expressing their feelings as a way to feel empowered to cope with their stigma. Makoe and colleagues (2008) reported that PLWHA used the educating themselves and others as strategies to deal with the condition.

In summary, the findings of this study show that HIV-related felt stigma is detrimental for the physical and psychological well being of PLWHA. In addition, it has negative consequences for the quality of life of this population. It adversely impacts the social, biological, interpersonal and intrapersonal areas of the individuals with the condition. Furthermore, the content analysis of these focus groups helps the researchers have a better understanding of the stigma perceptions of PLWHA in PR. It also served to culturally and linguistically adapt an instrument to measure felt stigma among this population.

"If any person that's listening to this tape has not been rejected, then do not reject anybody ... Because we have boxed the humans beings in, that's why we are living as we are living; because of a diagnosis...I am not a diagnosis I am a human being..."

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