

## The Face of Felt Stigma: Experiences of Puerto Ricans Living with HIV in Allentown, PA

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# The Face of Felt Stigma: Experiences of Puerto Ricans Living with HIV/AIDS in Allentown, PA.



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## INTRODUCTION

Felt Stigma refers to the perception of a real or imaginary social disqualification or the limitation of opportunities with a negative change in self perception (Berger, 2001). Literature has clearly demonstrated the negative impact of this phenomenon in the quality of life of people living with HIV/AIDS (Cameron, 2000; Chesney & Smith, 1999; Herek, 1999; Herek, Capitanio & Widaman, 2002; Moneyham et. al., 1996; UNAIDS, 2010).

Qualitative and quantitative findings from previous studies in Puerto Rico have established the multi-dimensional implications of felt stigma in people living with HIV/AIDS on the island. However, few studies have reported findings about felt stigma in the Hispanic/Latin population living in the U.S.

The objective of this qualitative study was to explore the experiences of HIV-related felt-stigma among a group of Puerto Ricans living with HIV/AIDS in Allentown, Pennsylvania, as well as document the participants' attitudes, perceptions and feelings generated from these experiences. The information obtained through a series of focus groups will inform the cultural adaptation of the HIV Felt Stigma Scale (Jiménez et al., 2010) to be used in Puerto Ricans living in the Main Land.

## METHODS

### PARTICIPANTS

Thirty five (35) Puerto Ricans with HIV/AIDS were recruited from the Lehigh Valley Network in Allentown, Pennsylvania. Four focus groups were conducted. Two groups were composed of men (n=15) and two of women (n=20). All participants met the following inclusion criteria: adults 21 years and older, established diagnosis of HIV infection, self-identification of Puerto Rican descent, and able to provide informed consent to participate in the study. The demographic data of the participants will be presented in Table 1.

### PROCEDURE AND ANALYSIS

After obtaining the participant's consent, four focus groups were conducted, in Spanish, for about 90 minutes. All groups' discussions were structured following a series of guided questions. Meetings were recorded, transcribed and analyzed. Notes were also taken with the purpose of documenting relevant aspects of the discussion (e.g. participants' non-verbal language). These notes were part of the analysis.

Information obtained from the focus groups was subject to qualitative analysis. Transcripts were reviewed by two researchers with the purpose of ensuring the authentic reproduction of the participants' discourse. The information obtained was scrutinized through content analysis, and reviewed to ensure that discourses were associated with the themes selected by researchers (Strauss, 2003). All selected information was coded using the qualitative analysis software ATLAS. ti.

TABLE 1 Sociodemographic data of population						
	N	%	N	%	N	%
<b>Age (years)</b>						
30-39	1	7	4	20	5	14
40-49	8	53	11	55	19	54
50-59	6	40	5	25	11	31
<b>Birthplace</b>						
Puerto Rico	7	47	11	55	18	51
USA	8	53	9	45	17	49
<b>Educational Level</b>						
Elementary School	0	0	1	5	1	3
Middle School	1	7	1	5	2	6
High School	11	73	13	65	24	69
Undergraduate studies	3	20	0	0	3	9

### FOCUS GROUPS GUIDING QUESTIONS

- When you hear the word stigma, what is the first thing that comes to your mind?
- Do you remember having any experience in which you felt “rejected”?
- How did you feel during those experiences of rejection?
- Have you shared your diagnosis with others?
- If you have not shared your diagnosis, why not?
- How have others reacted when you shared your diagnosis?
- How would you have like others to react?
- What change did you observe in others when you shared your HIV status?
- What did you thing of others with HIV before you received your diagnoses?
- What other things about rejection would you add to the discussion?

## RESULTS

### DEFINITIONS OF STIGMA

*“I think it is something that you feel, because it's something you think that people believe you are; whether it be positive or negative.”*

*“Fear of what others might say; a feeling, self-esteem...”*

*“Well, I think of what other people think about my private life, what I do and what I say.”*

*“For me, stigma is a stamp that others post upon oneself.”*

### THEME 1. EXPERIENCES OF REJECTION

Participants identified several experiences of rejection

*“You try to get a job out there; you are looking for a job... There are times you say: I am HIV positive, they won't choose you, they don't care about what anybody says...”*

*“...Then my sister-in-law (that's how she says) - I went to her house and stayed for the night and as soon as I woke up she took out the bed sheets and plastered them with ammonia, she did the same thing with the silverware I used.”*

### THEME 2. EMOTIONAL REACTIONS RELATED TO FEELING REJECTED

Participants commented on some emotional reactions after the experience of feeling rejected.

*“Oh, my God! How did I react? I felt bad because I was afraid of being isolated at home.”*

*“I feel frustrated. I am afraid of hurting people, I don't enjoy people as I should.”*

*“It makes you feel horrible, ashamed, angry, embarrassed, and contagious; like you're a walking disease, you know? Everything is negative and what came into my mind was very negative, There's no room for the positive, no room for the positive. When somebody rejects you there is no room for positiveness.”*

### THEME 3. EXPERIENCES REVEALING THEIR DIAGNOSIS

Participants expressed their fear related to the rejection of others.

*“I constantly think about how people see me and the way they think about me.”*

*“...Before I, when I knew I was ill, I was afraid of telling my son. There was a time, because of the possible rejection of my children and all...”*

*“Right now one of my sons is nineteen years old and he still doesn't know I'm ill, because I am afraid of telling him... I think he will reject me.”*

### THEME 4. PERCEIVED REACTIONS FOLLOWING PERSONAL DISCLOSURE

Participants revealed how they felt others reacted after sharing their diagnosis.

*“The first time they told me I was ill, I told my father. He acted so gravely that I knew he was going to reject me.”*

### THEME 5. COPING WITH FELT STIGMA EXPERIENCES

Participants commented on educating others to handle experiences of rejection.

*“What I do is, what I do is that I let him speak, I let him speak, I let him speak. I encourage forgiveness, I educate and broaden his mind.”*

*““We are going to take something positive from this, do you understand? We are going to take something positive. You already know you are in this situation; You can help other people who are ignorant towards this. When you hear a friend speaking of someone who is HIV positive, correct him.”*

### THEME 6. STIGMATIZATION

Participants reported feeling stigmatized by themselves as well as indirectly by others

*“I have felt rejected by myself. I rejected myself in the first two years that I knew... I was always cleaning with Clorox and throwing things out every day because I was very ignorant in respect to this disease. I didn't know anything about this disease, nobody talked about that disease.”*

*“In those days I was thinking, I was struggling to tell him what was going on, you understand? ...And that day, he comes up and says: I wish they would all die, they should be taken to another island and blown up. And I said Wow! ...So he who made me hopes that I would rather die. I took it very personally; I didn't take it as if he was speaking about them.”*

## CONCLUSIONS

- The vast majority of participants reported feeling rejected by family and health care providers.
- Findings indicate that felt stigma may have a multidimensional impact on self-concept, community and family life, relationships, and emotional well being.
- These findings suggest an urgent need to develop culturally sensitive interventions to address felt stigma in order to improve the quality of life of people living with HIV/AIDS.

*“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 a diagnosis...I am not a diagnosis I am a human being...” . Anonimus, 2008.*