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**FAMILY INTERACTION AND SOCIAL STIGMATIZATION OF PEOPLE LIVING  
WITH HIV AND AIDS IN PUERTO RICO**

***INTERACCIÓN FAMILIAR Y ESTIGMA SOCIAL EN PERSONAS QUE VIVEN CON  
VIH Y SIDA EN PUERTO RICO***

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## Abstract

This article aims to describe the manifestation of HIV stigma in the family context and how this could impact the life of people living with HIV (PLWH). The data derive from a larger phenomenological study addressing manifestations of stigma in the lives of PLWH when interacting with the health sector. Nine focus groups were carried out in 2011 with PLWH (N=67). Eight themes emerged from the qualitative analysis. For the purpose of this article, we focus on the categories related to family dynamics: the negotiation of disclosure and non-disclosure, fear of the HIV virus and family dynamics, and life as a couple. Socio demographic information showed that 53% were between 44 to 54 years old, 80% were single, 51% were male, 42% did not complete a high school diploma, 82% were unemployed. Also, 82% described themselves as religious persons and 41% had lived with HIV for 10 years or less. Qualitative results show stigma is still present in the family context. PLWH experience fear of disclosure, discrimination, avoid initiating families or couple relationships, experience physical and verbal abuse from relatives, and even separation from other family members. After more than 30 years of the ongoing HIV epidemic, stigma is still manifested by family members with detrimental social and medical implications for PLWH. Research and educational efforts should continue addressing manifestations of stigma among family members of PLWH.

## Resumen

*Este artículo tiene el propósito de describir las manifestaciones de estigma hacia el VIH en el contexto familiar y como ello pudiera impactar la vida de las personas que viven con VIH (PLWH). La data emana de un análisis de datos de una investigación fenomenológica más amplia que aborda las manifestaciones de estigma en la vida de las personas que viven con VIH en el escenario de la salud. Nueve grupos focales fueron realizados en el 2011 con PLWH (N=67). Ocho temas emergieron del análisis cualitativo. Para propósitos de este artículo, enfatizaremos en las categorías relacionadas a las dinámicas familiares: a) la negociación de revelar o no revelar la condición, el miedo al virus del VIH y las dinámicas familiares, y vida en pareja. Datos sociodemográficos demuestran que el 53% estaban entre los 44 a 54 años de edad, 80% eran soltero, 51% eran de género masculino, 42% no completó un diploma de escuela superior, y 82% estaba desempleado. Además, 82% se consideraba una persona religiosa, y 41% había vivido con VIH por 10 años o menos. Resultados cualitativos muestran que el estigma se encuentran aun presente en el contexto familiar. Las personas que viven con VIH experimentan miedo a revelar condición, discriminación, evitan iniciar relaciones familiares o vida en pareja, experimentan abuso físico y verbal de familiares. Luego de 30 años de la condición del VIH, el estigma aún se manifiesta a través de los familiares de personas que viven con VIH, teniendo implicaciones sociales y médicas perjudiciales para ellos y ellas. Esfuerzos investigativos y de educación deben continuar abordando las manifestaciones del estigma entre familiares de personas que viven con el VIH.*

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KW.- Stigma, HIV, Familism, Puerto Rico

PC.- Estigma, VIH, Familismo, Puerto Rico

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## **Introduction**

According to the Center for Disease Control (2012) 1,111 new cases of HIV infection were reported in Puerto Rico in 2010. As of July 2015, Puerto Rico's HIV Surveillance Program reported a total of 46,402 children and adults living with HIV; males represent 74% of HIV diagnosis and women 26%; the primary means of transmission in Puerto Rico is through unclean needle sharing among intravenous drug users (44%) (Department of Health, 2015). Although HIV infection itself is difficult to manage due to the physiological, emotional and health challenges that it entails (Basavaraj, Navya, & Rashmi, 2010), the experiences of being marginalized and dehumanized as a result of stigmatizing social and cultural beliefs regarding HIV and AIDS can complicate or even magnify these clinical concerns due to their impact on treatment, overall health and well-being (Parker & Aggleton, 2003).

### **1. What is social stigma?**

Erving Goffman (1963) defined social stigma as a discreditable attribute that can lead to the dehumanization of a person, who in turn experiences social rejection and stereotyping. Stigma can generate negative responses or undesirable effects among stigmatized individuals, affecting their ability to coexist in society. It can generate diverse feelings among stigmatized people such as shame, culpability, and social isolation. Goffman's sociological theory of stigma proposes that social interactions are shaped by definitions assigned to historically marginalized people and their behaviors (Robbins, Chatterjee & Canda, 2006). Goffman (1963) identified three sources of social stigma: a) abominations of the body, b) blemishes of individual character, and c) tribal stigmas. Abominations of the body refer to experiences of stigma due to the subject's physical deformities, such as people with physical impairments. The second source of stigma refers to those experiences of stigma related to a person's behavior or history of institutionalization (eg. prisoners, institutionalized psychiatric patients, and drug users). The third source is related to race, religion, or a person's nationality. In the context of HIV, the condition continues to be associated with socially marginalized and oppressed groups such as sex workers, men who have unprotected sex with other men and illicit drug users.

Social stigma in HIV refers to prejudice, discrimination, and discredit toward people who are perceived to be HIV positive and to people or groups with whom they are associated (Herek, 1999, 2002; Herek & Capitano, 1998; Salter et al., 2010; Ruiz Torres, Cintrón-Bou, & Varas-Díaz, 2007), including the immediate family. Social perceptions of HIV as a contagious, terminal disease that targets “immoral” persons or behaviors has detrimental effects on PLWH (Green & Sobo, 2000), especially on their adherence to treatment, willingness to disclose HIV serostatus, health seeking behaviors, and access to HIV counseling and testing, among other health-related outcomes (Katz, et al., 2013; Levi & Surrat, 2015; Parker & Aggleton, 2003; Scanlon & Vreeman, 2013; Velloza, et al., 2015).

HIV stigma can also affect the family (Morrison, 2006), a fundamental source of support for PLWH. According to Flores, Almanza & Gómez (2008), now that PLWH have a longer life expectancy due to the evolution of antiretroviral treatment, families continue to be essential providers of support. However, social stigmatization toward PLWH themselves as well as their relatives, combined with other social and economic factors, family members may feel limited in their skills and resources to support PLWH. Tensions between familial support and HIV stigmatization can produce a wide range of responses within families as stigma receivers but as sources of stigma against PLWH as well (Escobar & Balseca, 2017). The implications and outcomes of these tensions have been understudied in Puerto Rico (Varas-Díaz, Serrano-García, & Toro-Alfonso, 2005).

## **2. Familismo and HIV stigma**

Family is an important element in the health of Latinos (Ayón, Marsiglia, & Bermudez, 2010; Padilla & Villalobos, 2007; Valdivieso, Peet, Garnier, Salazar & Johnson, 2016). Families usually face an illness process as a unit, taking on socially constructed roles among women and men (González, et al. 2012; Padilla & Villalobos, 2012). This set of cultural beliefs, often referred to as familismo (Congress & González, 2013), privileges loyalty, closeness and the importance of contributing to the family nucleus, extended family and friendships (Bardis, 1959; Burgess, & Locke, 1945; Guilamo-Ramos, et al., 2007). The concept of familismo was introduced in 1945 by Burgess and Locke. Initially, the concept was defined as a value that characterized the social structure of more traditional societies when compared to the individual focus of modern urban societies. Although it was not initially focused on Latinos, over the past decades the concept has been primarily used to characterize this community

(Stein, et al., 2014). It has been defined “as a core value that requires the individual to submit to a more collective, family-based form of decision-making, responsibility for, and obligation to, ensuring the well-being of family members” (Smith, Morales-Campos, Castañeda, & Turner, 2012, p. 37).

HIV research studies have evidenced that family support can influence treatment adherence (Vera y Estrada, 2004), the ability to obtain an HIV test, participation in HIV-related educational services, or the opportunity to act as advocates for favorable policy changes (Li, et al., 2006). Also, familismo can influence the ways in which some family members come to terms with an HIV diagnosis of one of their relatives and the strategies for disclosure that are used in the family context (Serovich, Craft & Yoon, 2007).

In Puerto Rico, according to Ortiz, Serrano & Torres (2000), the concept of familismo was first used in research to “describe a high degree of interpersonal bonding within the Puerto Rican family resulting in greater identification with the group and dependence on the family” (p. 863). For Puerto Rican women’s health, this is a particularly important dimension that needs to be considered since family protection and care-giving have been socially constructed as primary roles for women. A study conducted in 2000 with Dominican and Puerto Rican women exploring the role of culture in HIV prevention shows that familismo can support HIV prevention (Ortiz, et al, 2000). On the other hand, HIV stigma research in Puerto Rico has also documented that family members can hold negative attitudes towards those living with the disease (Varas-Díaz, et al., 2005; Rodríguez Madera & Varas-Díaz, 2012).

In summary, a significant number of research studies have focused on the role of attitudes, knowledge, and perceptions in fostering HIV stigma and have documented its effects on PLWH in Puerto Rico (Rivera-Díaz, Varas-Díaz, Reyes, Suro y Coriano, 2012; Varas-Díaz, Malavé-Rivera & Cintrón-Bou, 2008; Varas-Díaz, et al., 2014; Varas-Díaz, et al. 2017). Even though studies addressing family aspects of HIV stigma have been conducted (Flores, Almanza, & Gómez, 2008; Ogunmefun, Gilbert & Schatz, 2010) few have been carried out in Puerto Rico (Ortiz, et al., 2000; Rodríguez Madera & Varas-Díaz, 2012; Varas, et al., 2005). In this study, we explored the experiences and manifestations of HIV stigma within the family context of PLWH in Puerto Rico and what this means for their lives, including health.

### 3. Method

#### 3.1. Participants

Data analysis of a larger phenomenological study conducted in 2011 addressing behavioral manifestations of HIV stigma among health professionals revealed family interaction and stigmatization as important and interrelated factors that influence the experiences of PLWH. The phenomenological perspective has been used to focus on the study of the lived experiences of those individuals with an illness (Palacios & Corral, 2010). It addresses the circumstances of an illness experienced by the subjects and tries to describe the meanings ascribed by people to the experienced phenomenon through an in-depth analysis of their descriptions (Trejo Martínez, 2010). A phenomenological approach allows us to understand situations from the subject's perspectives, without pre-established hypotheses or pre-conceptions. This article contains the analysis of these emergent categories as an important piece for understanding the implications of stigma. The study was approved by the Institutional Review Board for the Protection of Human Subjects in Research at the University of Puerto Rico (IRB #1011-097), and it consisted of nine focus groups of PLWH (N=67) with a range of 7 to 8 participants for each group (Kitzinger, 1995). A total of 67 male and female participants were recruited in an specialized HIV clinic in the Municipality of San Juan, Metro area with the following inclusion criteria: a) 21 years of age or older; b) living with HIV at the time of recruitment; c) under HIV treatment at the time of study; d) infected with HIV through the 3 mains routes of infection in Puerto Rico (unclean needle sharing for injecting intravenous drugs, unprotected heterosexual intercourse, unprotected sex among men who have sex with men); and e) having reported experiences of stigmatization and/or discrimination. See table 1 for the main description of the participants.

Table 1.- Sociodemographic description

<b>Characteristics</b>	<b>%</b>
<b>Age</b>	
22-32 years	3%
33-43 years	32%
44-54 years	53%
55-65 years	11%
66 and over	1%

<b>Characteristics</b>	<b>%</b>
<b><i>Gender</i></b>	
Male	51%
Female	49%
<b><i>Civil status</i></b>	
Single	80%
Married	9%
Widow	8%
Other	3%
<b><i>Municipality of residence</i></b>	
Bayamón	1%
Carolina	1%
Guaynabo	3%
San Juan	80%
Trujillo Alto	4 %
Others	11%
<b><i>Level of education</i></b>	
First to 8 <sup>th</sup> grade	22%
Some high school	20%
High school diploma	29%
Associate degree	22%
Bachelor degree	3%
None	2%
Other	2%
<b><i>Employment</i></b>	
Employed	18%
Unemployed	82%
<b><i>Income</i></b>	
Less than 1,000	79%
From 1,000 to 10,000	15%
From 10,000 to 20,000	3%
From 20,000 to 30,000	3%

<b>Characteristics</b>	<b>%</b>
<b><i>Religiousness</i></b>	
Considered themselves a religious person	84%
Not consider themselves a religious person	16%
<b><i>Health insurance</i></b>	
Yes	99%
No	1%
<b><i>Mode of HIV transmission</i></b>	
Women infected through unclean needle sharing among intravenous drug users.	15%
Males infected via unprotected sex with other males.	21%
Men infected through unclean needle sharing among intravenous drug users.	31%
Women who reported being infected via multiple routes of transmission (including heterosexual unprotected sex and blood transfusion).	33%
<b><i>Time living with HIV</i></b>	
1-5 years	24%
6-10 years	17%
11-15 years	12%
16-20 years	23%
21-25 years	14%
26-30 years	10%

### **3.2. Instruments**

The socio demographic questionnaire included 23 items divided in two parts: a) socio demographic information and b) experience living with HIV (see table 1).

A focus group guide with six (6) open-ended questions addressing stigmatization experiences was used to guide the discussion (see table 2).



Table 2.- Instruments implemented and main questions.

Instruments	Questions
<p><i>Sociodemographic questionnaire</i></p>	<p><i>I. Socio demographic information</i></p> <ol style="list-style-type: none"> <li>1. Age</li> <li>2. Gender</li> <li>3. Civil status</li> <li>4. Municipality of residence</li> <li>5. Level of education</li> <li>6. Employment</li> <li>7. Type of employment</li> <li>8. Monthly income</li> <li>9. Social support</li> <li>10. Do you consider yourself a religious person?</li> <li>11. Religion participation</li> </ol> <p><i>II. Experiences living with HIV</i></p> <ol style="list-style-type: none"> <li>12. Health insurance</li> <li>13. Type of health insurance</li> <li>14. Mode of HIV transmission</li> <li>15. Time living with HIV</li> <li>16. Experienced discrimination</li> <li>17. Person(s) who discriminated against you</li> <li>18. Viral load</li> <li>19. CD4</li> <li>20. Are you on treatment?</li> <li>21. Type of treatment</li> <li>22. Currently taking medications for HIV</li> <li>23. Type of medications</li> </ol>
<p><i>Focus group guide</i></p>	<ol style="list-style-type: none"> <li>1. When you hear the word “rejection”, what does it mean to you?</li> <li>2. What type of stigmatizing experiences you have had in the past?</li> <li>3. What would you describe as adequate behavior from a physician or health professional towards a person living with HIV?</li> <li>4. What are things physicians do that you understand could be based on stigma towards people living with HIV?</li> <li>5. How do these stigma behaviors vary depending on how that person became infected with HIV?</li> <li>6. Are there any other themes that you would like to discuss in relation to this topic or other?</li> </ol>

The guide was designed and evaluated by HIV researchers in Puerto Rico and co investigators of this study. Its purpose was to: (1) explore detailed stories of stigmatizing

experiences faced in the past, and (2) identify specific behaviors manifested by physicians that they perceived as being motivated by stigma. All the focus groups were conducted in Spanish by the first author and two research assistants. At the end of the focus group, each participant received a twenty dollars' stipend for meal and transportation costs.

### **3.3. Approach**

Flyers promoting the project with the researcher team's contact information were posted on the clinic's bulletin boards. Also, the research team visited the clinic for a research project orientation and participant recruitment. Once participants stated their availability to participate in the study, researchers evaluated participant's inclusion criteria and scheduled an appointment for the focus groups. We used a focus group technique to facilitate a discussion with PLWH in order to explore their experiences of discrimination and stigma. Participants were assigned to focus groups according to their self-reported means of HIV transmission (i.e., intravenous drug use with unclean needles, unprotected sex, and multiple means of transmission). Stratifying the groups by mean of transmission and gender was determined to be preferable in order to gather diverse stigma experiences that could be influenced by these categories. During the focus group meetings, all participants signed an informed consent form and completed a socio-demographic questionnaire.

Nine focus groups were carried out in 2011 with people living with HIV (PLWH) (N=67), divided according to their reported mean of transmission: a) two groups of men infected via unclean needle sharing for injecting illegal drugs (n=21); b) three groups of men infected via unprotected sex with men (n=14); c) three groups of women who reported infection via multiple transmission routes (e.g. heterosexual relations without protection and blood transfusions) (n=22); and d) a group of women exposed to HIV via unclean needle sharing for injecting illegal drugs (n=10). Focus groups were between one and a half to two hours in length. All the focus groups were digitally audio-recorded and later transcribed *ad verbatim* by the research assistants using the software program HyperTRANSCRIBE. All the transcriptions were revised for accuracy by the principal author.

### **3.4. Data analysis**

After all the data were transcribed, a triangulated analysis was completed by the research team. This triangulation method for data analysis and data interpretation involved four

research assistants and the principal investigator in the thematic analysis of the focus groups (Hussein, 2009). In this analytic process, the research team members began by conducting separate individualized coding of a set of the transcribed interviews to identify narratives related to the experiences of HIV stigma. After this individualized coding process was completed for a set of transcripts, multiple research team meetings were conducted to discuss the coding, resolve any questions or disagreements emerging, and develop our collective analysis of major themes related with the study (Bernard, 2006; United States Agency for International Development, 2010). The stigmatizing experiences with family members was an emergent category during the thematic analysis of the larger study. Specific analytic categories were then constructed to denote central themes that were critical for our project, and definitions of each theme were elaborated into a codebook. At this point, transcribed interviews were re-coded using the codebook. From the data analysis, a total of eight main categories that addressed family experiences emerged: 1) fear of infection and family dynamics, 2) family's isolation, 3) non-disclosure, 4) family support, 5) HIV education among family members, 6) bodily marks or signs of HIV, 7) life as a couple, and 8) family's disclosure of HIV condition to outside "others". Nvivo software, version 8 was used for coding purposes after finishing the coding process manually. This allowed us to work with themes across all the focus groups. Below we report on three of the above central themes which were most closely related to family dynamics and HIV stigma. Due to the complexity of HIV stigma and its multiple forms of expressions in the family context, in this paper we concentrate on the discussion of three selected themes. Other themes will be addressed in future publications.

#### **4. Results**

Participants' verbalizations related to the issues of family and HIV stigma experiences emerged in specifically three categories of our data analysis. These included the following: a) negotiation of disclosure and non-disclosure b) fear of infection and family dynamics, and c) life as a couple. Verbalizations are identified with acronyms that represent each participant according to their reported means of HIV transmission followed by an individual number for each participant: a) MSM means male infected via unprotected sex with male; b) MIDU means male infected via intravenous drug use; and c) WMRT means women reported infection via multiple transmission routes.

#### 4.1. Negotiation of disclosure and non-disclosure

This category includes verbalizations from participants describing their indecision regarding disclosure of their HIV infection to family members for fear of being rejected or fear of disclosure by others without their consent. It also includes experiences of being exposed to HIV by partners who did not disclose their positive status to them. One of the participants in the MSM group expressed that he was exposed to the virus by his partner without knowing he was HIV positive and assuming the relationship was monogamous or that there was a general perception of fidelity and confidence:

*“When I came [to Puerto Rico] in 2005 I had a partner for 10 years. I thought I had a stable relationship, but the person had the condition [HIV infection] and never told me anything. And you say there are 10 years, you know...I went to the Municipal Tower...they provide free HIV testing, well I am in my work, I called him to come and do the test together because we have been together for 10 years. I see he does not show up and I waited until end...So, I did the test...when I went there, it was positive. The results indicated that the person I was dating had it [HIV] for more than 6 years and that made me feel very sad because I considered it a waste of time because he could not be honest with me and told me, you know...he had his pills in Humacao, in his mother’s house. I see persons that have relations and you can see that tendency too...when I have the opportunity, I try to counsel people not to trust others so easily because [people] cannot be as confident as I was. It hurts when a person leaves you and infects you” (MSM 50).*

Other participants in the MSM group described how they preferred not to disclose their HIV status for fear of being rejected by their family members:

*“When I found out about the condition... I was diagnosed in jail. When I got out I did not feel comfortable telling my family. My brother, who was a drug user, came to my house and my mom had a dish, a spoon, a fork and a cup for him. When I went to eat from that dish, she told me: ‘Hey, do not eat from that dish. That is for (brother’s name). You don’t know if he has AIDS’. So, how I am going to tell her I am [HIV] positive?” (MSM 31).*

Also, a participant expressed an experience with his sister disclosing his HIV infection without his consent. He felt the disclosure was related to her discrimination against him for his HIV infection.

*“I had a problem. I had trouble with my sister because my sister discriminated against me and then I said, well then... you know that she was coming to my house when she needed [something]. So when she found out that I had the condition, she came and said ‘you have to take care of the condition’ and then she told everyone. Then I got angry with her because she should not have told anyone” (MIDU 8).*

## 4.2. Fear of infection and family dynamics

This theme includes verbalizations that describe specific manifestations of how relatives of PLWH use excessive hygiene, such as disposable utensils and constant disinfection of common household areas like bathrooms, due to fear of infection. Within this theme, participants across all groups often reported how family members avoided physical contact with them. In particular, the use of separate dishes and eating utensils was a common means by which HIV stigma was expressed in family environments. The following interview illustrate this theme:

*“My mom always rejected me and she rejected me because of the condition. She always had everything separate for me... cup, fork, knife. Everything separate. That was painful because she was my mother. It is painful and since then I have felt trauma over this” (WMRT 49).*

*“The discrimination, the rejection that I felt from... my boss and my family. Even today I use my own fork, my own dish and if I use another one they give me a lot of grief over it. You know, I feel uncomfortable” (MIDU 145).*

The social perception of HIV as an "unclean" condition in a "contaminated" body was commonly expressed in the narratives of these participants' experiences with their families. We did not find differences among groups on how family members implemented excessive hygiene as a means of protecting other family members from an individual family member's presumed infectiousness. Participants mentioned the following:

*“...because they believed that even using the same shower (another participant interrupted and said: "That happened to me") ...the ignorance! Even using the same shower or toilet... they came and cleaned it with "Clorox" [disinfectant bleach]. You know, that was painful” (MIDU 121).*

In the case of women, fear of contagion also extended to the interpretation of maternal roles. This included extremely painful experiences of children leaving their houses as soon mothers disclosed their HIV status and of other family members separating them from their children. These experiences were unique in the focus groups with women.

*“I had to search for a psychologist for her [daughter] and for me, so I could tell her that I was infected by her dad. She carries a stigma, she was scared of me, she did not eat... She used to sleep with me and she doesn't anymore. She left my home and went to live at another house, where the person also had the condition... and the person, because she loved her so much, told her: 'but, why you are here?' She said: 'because my mom has HIV. The person responded: 'but I have HIV too,*

*and I am doing fine thanks to your mom'. So she understood a little bit more and she always calls me and asks 'mom, what are you doing? Are you ok? Are you feeling ok?' So, now she takes care of me more because she understands" (WMRT 29).*

The above case illustrates that sometimes the initial stigmatization of a woman living with HIV can contribute to growth and understanding, although not before going through a process that is often characterized by fear and stereotyping.

Some women reported having their children taken away by other family members as a result of their HIV disclosure.

*"I knew about my condition. I was... incarcerated I did not pay attention. After I got out I went to a program. After the program was finished and I went to my house, I was living with my grandparents at that time. So somebody called my house. I was not there so my grandfather answered. He [grandfather] received the news [she was HIV positive]. When I came back in the afternoon, he told me: 'You cannot enter this house'. He said: 'Umm, because they called, the place where you were studying, and said you had AIDS'. Well, he left me out on the street. I could not enter. He took my kids away from me. I could only see them through the gate. He gave me food in disposable dishes, and if I did not bring the dish, I did not eat...he gave me the food through the gate" (WMRT 37).*

The interviews emphasized the extremely painful process emerging from lack of information and fear, through which family members began assimilating the information about their loved one's HIV infection. While interviewees recognized these reactions as a consequence of ignorance or lack of education, they nevertheless suffered intense injustice and symbolic violence at the hands of their families.

### **4.3. Life as a couple**

This category includes manifestation of concerns over creating a family unit or having a partner due to their HIV status. Participants in all the focus groups expressed fear of having a relationship or being in a couple for four main reasons: 1) it placed partners in a more vulnerable health position, 2) fear of being rejected by a potential partner when HIV status was disclosed, 3) previous experiences with partners who ended relationships due to HIV status and 4) fear of being accused of HIV transmission to a serodiscordant partner. Participants illustrated these themes in discussions about their relationships.

*"Today, nobody wants to have an HIV positive partner. Everybody says that you can continue your normal life but if someone knows, that person is not going*

*anywhere. If you know that the girl is positive, you are not going to be with her. You are scared of even giving her a kiss. It is the same with homosexuals. They do not want to have [sex], even with condoms. Because it is still a mystery where AIDS came from, you know. Currently, it is transmitted by homosexual relations... by syringes... but it is a mystery where it came from” (MSM 537).*

Another male participant similarly described a dramatic situation that occurred with his wife while he was ill with an HIV-related condition: “I was married when I was at the hospital with pneumonia. She told me: ‘if you have the condition, I don’t think I can be with you’. Still, I face that. Thank God I am alive” (MIDU 109). Concern over being accused of HIV transmission to a seronegative partner was mostly expressed by women:

*“...if the person that does not have [HIV] does not want to protect him or herself... and in the future that person gets the condition and decides to blame you. I have had the condition for 20 years and I have a partner and I explained to him: ‘...look, I have had HIV since this time, you have to protect yourself.’ So, we have been using protection for 3 months and then he said ‘no (more protection), this is over. I will stay with you for the rest of your life.’ I do not want problems, so I made him sign a document that I have in my house, as a sense of responsibility. ‘I explained it to you, I told you, you wanted it, it’s your responsibility...” (WMRT I25).*

## 5. Discussion

The purpose of this study was to describe the manifestation of HIV stigma experiences in the family context and how these could impact the life of people living with HIV (PLWH). Socio demographic information shows that 53% were between 44 to 54 years old, 80% were single, 51% were male, 80% lived in the San Juan Municipality, 42% did not complete high school, and 82% were unemployed. Also, 82% of participants described themselves as religious and 41% had lived with HIV for 10 years or less. Results from our qualitative study evidenced that stigma is still present in the family context in Puerto Rico. PLWH experience fear of disclosure, discrimination, avoid initiating families of their own or couple relationships, experience physical and verbal abuse from relatives, and even separation from family members.

The decision to disclose HIV status to partners and families is mediated by the fear of being rejected or supported by their love ones. For Latinos, in this case the Puerto Ricans, family support is an important facet for facing many life difficulties. Research studies have documented the relationship between familismo and risk behaviors (Gil, Wagner & Vega,

2000). Family support, or lack thereof, could represent a trajectory toward living or dying for those living with HIV – alleviating their challenges or putting their health at risk. The decision not to disclose to family members is expressed by PLWH in this study, but research also shows that non-disclosure is a strategy implemented by relatives of PLWH to manage stigma from society at large. Research studies have also indicated that relatives maintain secrecy about the HIV status of their loved ones to protect them from stigma and discrimination (Flores, 2000; Li et al, 2008; Flores, Almanza y Gómez, 2008). Flores (2000) has pointed out that this decision could exacerbate social stigma in society at large by preventing open discussion of social inequalities and preventing opportunities for education. On the other hand, stigma literature indicates that relatives of members from socially stigmatized groups are stigmatized as well (Goffman, 1963). Family members' reasons for not disclosing could also be related to the fear of being discriminated against for taking care of PLWH and for being associated or identified with those socially marginalized groups and their presumably unacceptable behaviors.

Fear of contagion based on non-scientific knowledge (e.g. touching PLWH, sharing utensils, and kissing) is still present in the popular consciousness of the society as well as in family structures. This can influence a person's decision to disclose their HIV status. They expressed concerns over being rejected and not supported by their loved ones (i.e. immediate family such as parents, partners and sisters) based on social stigma about HIV still being present in the society. Those PLWH who decided to disclose reported they felt discriminated against and not supported by their relatives. This occurred without differences across all the focus groups, including those with women.

Though the literature on HIV in Puerto Rico sustains that familismo as a cultural aspect could play a positive role in HIV prevention (Ortiz-Torres et al, 2000), our study is consistent with other studies that have documented that family members can hold negative attitudes towards those living with the disease, producing painful life experiences among PLWH (Varas-Díaz et al., 2005; Rodríguez Madera & Varas-Díaz, 2012).

On the other hand, a woman living with HIV engaging with a partner as a couple could also highlight the disadvantaged position women hold in a patriarchal society (Rivera-Díaz et al., 2015). Taking into consideration this position, women expressed how they disclosed their HIV diagnosis to their partners and prepared “disclosure” documents to be signed by their intimate partner as an alternative to protect themselves against possible legal actions in case of HIV transmission. Women participants expressed feelings of guilt imposed on them by society for potentially infecting their male partners. In the case of women in long-term



partnerships and living with HIV, patriarchal discourse and familismo shapes the roles and responsibilities in the family organization through gender, increasing women's presumed responsibility for putting others at risk (Heyer, 2012). Women felt the responsibility to disclose their HIV status to their partners due to the fear of possible lawsuits. These findings reinforce the interpretation that women living with HIV are doubly disadvantaged. First, because of gender biases and the social construction of women's roles within the family structure and relationships where it is presumed they are responsible for others' health and for protecting them from HIV. Within the cultural notion of familismo, women are socially seen as the symbolic center of the family around which all the activities and family relationships revolve (Heyer, 2012). Mothers and wives who are HIV positive could be socially seen as destabilizers of the entire family structure and looked upon with scorn for violating their family care responsibilities. Second, in a society where women are called on to attend to their homes and put their family first before their health, where their bodies and sexuality have historically been defined through masculine and patriarchal meanings, women may feel the need to de-prioritize their own health needs, further compromising their capacity to combat the infection (Rivera Diaz et al, 2015).

After almost four decades of this epidemic, HIV continues to present challenges in the lives of PLWH due to social stigmatization and its association with death (Green & Sobo, 2000). The experience for those affected by HIV is worsened when the stigma is present in a society that is illiterate in terms of sexual health, is highly gender biased, and where drug use is severely criminalized (Parker & Aggleton, 2003). However, families could play an important and sometimes decisive role in how their loved ones deal with HIV and engage in care (providing housing, support in medical appointments, economic help, taking medicines, among others) (Green & Sobo, 2000; Li et al., 2006).

Finally, this study has some inherent limitations, mainly the use of data that emerged from a main study as a central source of information and the lack of a holistic family system perspective to assess stigmatization. Although focusing on the perspective of PLW is useful, it is imperative for social workers to explore the whole family system in order to develop future intervention strategies. Also, this is a qualitative methodology, focusing on the subjective experiences of participants and generalization is not intended. As researchers, we recognize that the described research study was conducted six years ago and the context of stigmatization in Puerto Rico may have undergone some transformation. However, analysis of data provides valuable information for future research on patriarchal discourse and culture in the context of HIV and stigma and allows us to initiate a discussion of possible

recommendations for the role of health professionals and social workers in this process. Future research should also consider the family members' perspective.

### **Recommendations for practice**

In order to understand and address these issues, social workers and other health related professionals need to advocate for extending the availability of diverse mechanisms of care for PLWH that allow professionals and clinicians to address issues such as dealing with the diagnosis, the negotiation of sex and intimate partnerships, disclosure to others, understanding the condition, and emotional distress of PLWH and their family members. This is particularly true for women, as has been demonstrated by previous health research studies within other cultures, such as among Chinese populations (Li et al., 2006), Latinos in the US (Dávila, Reifsider & Pecina, 2011; Vera & Estrada, 2004), and women in the Caribbean (Ortiz, et al., 2000). Inclusion of family members is part of the proposed diverse mechanisms of care for PLWH that could improve their overall health. Including family members in the process of health care with the consent of the PLWH, implementing PLWH's family support groups and PLWH peer support groups in medical and mental health scenarios could be promising practices. However, two specific actions to facilitate this process are required: a) to overcome limitations on coverage for those services by insurance companies recognizing them as an essential part of the PLWH treatment, and b) to educate future and current clinicians and other health related professionals on the importance of including the family members in the reduction of stigma, increasing social support and improving the overall health and well being of PLWH.

Fostering early education in elementary, secondary and high schools on HIV related stigma, HIV prevention, diagnosis and supporting an HIV positive loved one could help initiate a process to eradicate one of the biggest challenges around HIV. Institutions of higher education, health community clinics, hospitals, and mental health settings could be part of these educational initiatives and could provide education on HIV stigma, sexual life with serodiscordant couples, and similar themes to families and communities. We must strive to implement interdisciplinary approaches when working with PLWH and their families.

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