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# AIDS-Related Stigma and Social Interaction: Puerto Ricans Living With HIV/AIDS

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*People living with HIV/AIDS are stigmatized. Although personal and social consequences of this stigmatization have been documented, research regarding its impact on social interactions is scarce. Latinos, and Puerto Ricans in particular, have voiced concern regarding AIDS stigma. The authors investigated the key role of social interaction in the process of stigmatization through in-depth, semistructured interviews in a sample of 30 Puerto Ricans living with HIV/AIDS. Participants reported instances in which AIDS stigma negatively influenced social interactions with family, friends, sexual partners, coworkers, and health professionals. Some of the consequences they described were loss of social support, persecution, isolation, job loss, and problems accessing health services. Findings support the need for interventions to address AIDS stigma and its consequences.*

**Keywords:** HIV/AIDS; stigma; social interaction; Puerto Ricans

**T**he HIV/AIDS epidemic has posed multiple challenges to society in general (Gebbie, 1995). Some of these include HIV prevention (Kalichman, 1998a), working conditions for affected people (Brooks & Klasinski, 1999), access to health services (Havens, Mellins, & Ryan, 1997; Montoya, Bell, Richard, Goodpastor, & Carlson, 1998; Quintana Lloréns, 1998), and human rights protection (Gray, Lyons, & Melton, 1995). These challenges coexist with another epidemic that surpasses the biological dimensions of the virus: an epidemic of stigma (Epstein, 1992; Herek & Glunt, 1988).

Because of the expected increase in HIV cases by the year 2020, the stigma surrounding it is likely to intensify (National Institutes of Health, 2001). Research indicating that people still hold stigmatizing attitudes toward those living with HIV and AIDS (PLWHA) confirms this expectation (Herek, Capitano, & Widaman, 2002; Varas-Díaz, 2002). The need to address the stigma surrounding HIV/AIDS and its effects is evident (Albright, 2000; American Association for World Health, 2000; Fauschi, 2000; National Institutes of Health, 2000, 2001; Pisani, Schwartländer, Cherney, & Winter, 2000). Even though some researchers have signaled the need to explore the social dimensions of the epidemic, including stigma, the latter still requires attention.

## WHAT IS STIGMA? GOFFMAN'S CONTRIBUTIONS

One of the most widely used definitions of stigma was developed by sociologist Goffman (1963) and presented in his book titled *Stigma: Notes on the Management of a Spoiled Identity*. He defined stigma as a profoundly discreditable attribute that could lead a person to be deemed almost inhuman. He also identified three types of stigma: abominations of the body, blemishes of individual character, and tribal stigmas. Abominations of the body are stigmas associated with physical deformations or deviations from a social norm, such as people with physical challenges, missing limbs, or physical deformities, among others. Blemishes of individual character are stigmas associated to a person's character, identity, or simply his or her particular way of being. Some of these blemishes can be attributed to people in jail, drug users, alcoholics, and people with poor mental health, among others. Finally, tribal stigmas refer to the negative evaluation of particular persons because of their association with a group. Some of these stigmas are related to race, ethnicity, and sexual preference. All of these types of stigma can contribute to the devaluation of people who manifest them. Goffman's conceptual framework has been elaborated by researchers to address other aspects that might make a stigma more harmful. For example, the attribute that elicits negative social judgments from others can be worse for the stigmatized person if (a) it is not concealable, (b) it is deemed to be advanced in its course, (c) it is not aesthetically pleasing to the observer, (d) the stigmatized person or group is blamed for its origin, (e) it is associated with death, or (f) it disrupts social interaction (Jones et al., 1984; Murphy, 1995).

Goffman's (1963) conceptual framework on stigma has been used to explain stigmatization associated with issues of race, ethnicity, and physical disabilities. AIDS researchers have also recognized the important contribution of his ideas and have used them to explain the stigma surrounding HIV/AIDS.

## AIDS STIGMA AND ITS CONSEQUENCES

Living with HIV/AIDS can be one of the potential discreditable attributes described by Goffman (1963) in his conceptual framework on stigma. The magnitude of stigma associated with HIV/AIDS is reflected in the coining of the term *AIDS-related stigma* (ARS) or *AIDS stigma* (Herek & Glunt, 1988, p. 886). The myths that surround the HIV/AIDS epidemic contribute to this stigmatizing process (i.e., means of transmission, origin of the virus, among others) (Cunningham & Ramos-Bellido, 1991). Among the social meanings attributed to the epidemic, we find that HIV-positive people are sometimes perceived as invasive agents in a "healthy" society (Bunting, 1996; Sontag, 1990). This notion fosters the social exclusion of those perceived as risk agents, because they are interpreted as a threat to others, as deviating from what is "normal," and as a burden on society.

Researchers have documented the negative personal and social implications of AIDS stigma for PLWHA. Some of its negative psychological effects include anxiety, depression, guilt, isolation, disruption of family dynamics, physical and emotional violence, intensification of grief, loss of social support, and the deterioration of productive relations with health professionals (Chesney & Smith, 1999;

Kalichman, 1998b; Nord, 1997). AIDS stigma also has the potential to generate other situations that have negative effects on mental health, such as loss of health insurance, social discrimination, unemployment, and problems accessing health-related services (Herek, 1999; Leary & Schreindorfer, 1998). This potential social exclusion and discrimination associated with AIDS stigma demonstrates the need to address its consequences on social interactions with different people, in particular those individuals that are important to PLWHA.

### **The Key Role of Social Interaction in AIDS Stigma**

Scientists agree that to understand AIDS stigma, the perspectives of both the stigmatized and those who stigmatize must be explored (Herek, Mitnick, et al., 1998; Oyserman & Swim, 2001). This places the focus on the key role of social interaction in this conceptual framework. It is in their social interactions that stigmatized people are perceived as deviating from a social norm (Crocker & Quinn, 2000; Goffman, 1963; Luchetta, 1999). In the social interaction between the stigmatized and the nonstigmatized, the former might be perceived as having less influence or power (Jones et al., 1984).

The prevailing agreement of the importance of social interaction has not generated substantial additional stigma research on the subject. Some researchers have stated that the literature on stigma, including AIDS stigma, has not contributed to our understanding of the perspectives of either the stigmatized or those who stigmatize (Oyserman & Swim, 2001; Weiss & Ramakrishna, 2001). Research has focused more on the attitudes held by seronegative people toward PLWHA than on the perspectives of those directly affected.

Some research has documented negative consequences of AIDS stigma and the integral role of the interaction between stigmatized and nonstigmatized people (Hebl, Tickle, & Heatherton, 2000; Luchetta, 1999). Feelings of isolation due to AIDS stigma have been documented among serodiscordant heterosexual couples (Van Der Straten, Vernon, Knight, Gómez, & Padian, 1998). Avoidance of talking about HIV/AIDS, guilt, and loss of sexual interest have been documented among serodiscordant male couples (Remien, Carballo-Diéguez, & Wagner, 1995). PLWHA tend to mistrust others because of their stigmatizing experiences (Crandall & Coleman, 1992).

Other dimensions associated with social interaction and identified by researchers as important for understanding AIDS stigma include fear of contagion and controllability of infection. People might fear becoming infected with HIV and therefore avoid interaction with PLWHA. On the other hand, negative attitudes toward PLWHA are also closely linked to others' perception of their control over their possibility of infection. Some people feel that PLWHA "got what they deserved" and avoid contact with them (Capitano & Herek, 1999; Herek & Capitano, 1998, 1999). People that are perceived as having more control over their means of infection are more stigmatized and receive less empathy than those perceived as having less control (Batson et al., 1997; Menec & Perry, 1995; Peters, den Boer, & Schaalma, 1994; Rush, 1998). For example, attitudes might be more negative toward an HIV-positive sex worker than toward a housewife whose husband infected her. The sex worker might be perceived as being guilty or responsible for her infection, whereas the housewife is seen as an unsuspecting victim.

The scarcity of research addressing social interaction in the process of stigmatization is worsened by the absence of stigma research within Latino populations. Puerto Ricans have been particularly absent from AIDS stigma research during the past decades.

### **AIDS-Related Stigma and Latino Populations**

The call to develop culturally grounded research on AIDS stigma (Herek, Mitnick, et al., 1998) has not been widely acted on, as most published articles on the subject have not incorporated the Latino community in the United States or elsewhere. AIDS stigma among Latinos and Latinas must be addressed, particularly because of the severe impact the epidemic has had on this community. The numbers of AIDS cases reported by the U.S. Centers for Disease Control (CDC) among Latinos and Latinas are appalling. Even though they represent 12% of the U.S. population, they accounted for 19% of all reported HIV/AIDS cases by the end of 2000. During the same year, the incidence rate for Latinos and Latinas was more than three times the rate for Whites (CDC, 2002).

The numbers in Puerto Rico are alarming. The island has more than 29,205 reported cases of AIDS, of whom more than 18,370 have died (Oficina Central Para Asuntos del SIDA y Enfermedades de Transmisión Sexual [OCASET], 2004). Men represent 77% of these cases and women 23%. The most common means of infection are sharing needles for injected drug use (50%), heterosexual transmission (24%), and transmission between men who have sex with men (MSM) (17%). Along with Haiti, Puerto Rico accounts for the vast majority of AIDS cases in the Caribbean, which, in turn, has the second highest prevalence in the world (Pan American Health Organization [PAHO], 2001; World Bank, 2001). With an ever-growing number of HIV/AIDS cases, the plight of Puerto Ricans on the Island as well as the United States mainland must also be addressed, as migration further facilitates transmission of the epidemic between the two countries.

The Latino community has shown concern about AIDS stigma and has reported feeling that stigmatizing attitudes have intensified in the past 5 years and that access to HIV/AIDS services is limited because of stigmas related to race, gender, and poverty (Kaiser Family Foundation, 2001). The latter concern, and its combination with the consequences of AIDS stigma, evinces the need to develop research that aims to explore the phenomenon among Latinos and Latinas, particularly Puerto Ricans.

To address these issues, we had three objectives for this study: to explore (a) perceived instances of stigma by PLWHA in Puerto Rico, (b) the role of social interaction in the stigmatization process, and (c) the consequences of AIDS stigma on participants' daily lives and social relations.

### **METHOD**

Because of the exploratory nature of this research, its novelty in the Puerto Rican context, and previous recommendations by AIDS stigma researchers (Herek, Mitnick, et al., 1998), we carried out a qualitative study consisting of in-depth, semi-structured interviews with PLWHA.

## Participants

The sample consisted of 30 Puerto Ricans living with HIV/AIDS. The participants met the following criteria: adults (age at least 21 years) who were receiving HIV/AIDS services in a community-based organization (CBO), with knowledge of the way they were infected, who felt stigmatized because of their condition, and who lived in Puerto Rico when they were interviewed.

Participants were divided in three groups of 10 according to the most common HIV transmission categories in Puerto Rico. These are unclean needle sharing during injected drug use ( $n = 10$ ), unprotected heterosexual relations ( $n = 10$ ), and unprotected homosexual relations ( $n = 10$ ). These subdivisions allowed us to document a wide range of stigmatizing experiences, as each of the categories elicits different value judgments from society and generates different stigmatizing experiences. The group infected by injected drug use included 6 men and 4 women in proportion to the incidence of infection by drug use with regard to gender (OCASET, 2004). The group infected by unprotected heterosexual relations included only women, as they are the fastest-growing sector of the epidemic in Puerto Rico (OCASET, 2004), and research has shown particularly high levels of stigmatization among them (Santiago, 1998). Finally, the group infected by unprotected homosexual relations was composed of men, as they have been widely stigmatized in the past, and there are no statistics regarding HIV transmission among lesbians in Puerto Rico. Although the number of participants in each category might seem small (and in the subsequent gender division of those infected via injected drug use), it is important to note that we did not impose such a division on the sample to compare the groups or achieve representativeness. The analysis was carried out with the entire sample, and these divisions were meant to ensure some level of variability regarding stigmatizing experiences among participants.

The sample was almost equally divided among men ( $n = 16, 53.3\%$ ) and women ( $n = 14, 46.7\%$ ). The mean age for the total sample was 39; most were single ( $n = 19, 63.3\%$ ) and lived in the metropolitan San Juan area ( $n = 24, 80\%$ ). Regarding sexual orientation, 16 participants reported being heterosexual (53.3%), 12 were gay men (40%), and 2 were bisexual (6.7%). With regards to formal education, 14 people (46.7%) had completed high school, and 6 held a bachelor's degree (20%). Most participants were unemployed ( $n = 22, 73.3\%$ ), and their monthly income ranged from zero to US \$500 ( $n = 16, 55.2\%$ ). Ten participants reported living alone (33.3%), 9 lived with family members (30%), and 5 were homeless (16.7%). Nineteen participants (63.3%) reported undergoing antiretroviral therapy at the time they were interviewed. Ten were unaware of their viral load (33.3%), and 8 informed us that it was undetectable (26.7%). The length of time since diagnosis was reported as ranging from 4 months to 17 years.

## Procedure

The study's protocol was evaluated and approved by the University of Puerto Rico's Committee for the Protection of Human Subjects in Research (CAPSHI for its acronym in Spanish), which deemed it appropriate in its ethical standards and participant protection procedures.

Its implementation began with the recruitment of three interviewers who met the following criteria: (a) previously trained in HIV/AIDS-related subjects and

(b) possessed interviewing skills from participation in previous research efforts. All participated in a specialized training that addressed the following subjects: (a) definition and implications of AIDS stigma, (b) implementation of interviews with stigmatized populations, and (c) aims and objectives of the project and interview process. During this training, interviewers participated in a role-play exercise involving a trial interview. They were advised regarding the proper use of non-stigmatizing language and follow-up questions.

All personnel involved in the research project (i.e., interviewers and CBO personnel) were trained on the several data sheets used throughout the study to gather information from participants. These included a participant screening form, a demographic data sheet, and an in-depth, semistructured interview guide. The screening form included questions regarding inclusion criteria and contact information. Questions addressed participants' nationality, age, experience with HIV/AIDS services in a CBO, means of contagion, and stigmatization experiences. Because the concept of stigma might have been unknown to participants due to its academic nature, questions regarding stigma were phrased in a manner that documents the construct using keywords such as prejudice, exclusion, or persecution.

The demographic data sheet included questions regarding participants' economic status, age, sex, gender, area of residence, and education level. Participants completed the sheet in a 10-minute period before the interview. Finally, the in-depth, semistructured interview guide was composed of 40 open-ended questions. These questions addressed the personal experience of being HIV positive, situations in which participants have felt stigmatized, and skills they possess to cope with ARS. It was developed in light of an extensive literature review on ARS, its dimensions, and its consequences. After developing the initial version of the interview guide, it was evaluated by a panel of three HIV/AIDS research experts. They offered insight as to the phrasing of questions and structure of the guide. Afterward, we pilot-tested the guide by interviewing two PLWHA recruited from one of the aforementioned CBOs. Results from the pilot study evinced the need to simplify the phrasing of the questions further and add others related to social relations with health professionals and their stigmatizing attitudes. The semistructured format allowed interviewers some level of uniformity while also permitting them to follow up freely on specific thematic areas on which a participant might have wished to comment.

Participants were recruited from local CBOs who have traditionally worked with HIV/AIDS in Puerto Rico. We met with key personnel from each agency prior to participants' recruitment to train them on (a) the aims of the study, (b) participant recruitment process, and (c) eligibility criteria. They identified potential participants within their organizations and requested their participation in the study. They explained the nature of the study and what their participation entailed to all who wished to participate. Participants completed a short screening form (5 minutes to complete), administered by CBO personnel, to ensure that they complied with the selection criteria and to gather contact information (i.e., name and telephone number) used to schedule interviews with participants who wished to do so at a later time (confidentiality was assured by keeping the source of the call anonymous). People who wished to participate and met the eligibility criteria completed a CAPSHI-approved consent form informing them of the objectives and procedures of the study, filled out the demographic data sheet, and participated in the interview. Those whom the CBOs identified as ineligible for participation were thanked

for their interest and given informational materials on HIV/AIDS. Participants completed the interview process in approximately 1½ hours, after which they were given a US \$50 stipend. All interviews were conducted from May to July 2002.

### Data Analysis

The information gathered through the audiotaped interviews was transcribed, stored, and analyzed with the use of the QSR NVivo software, version 1.1. The unit of analysis was the theme, as it allows for the inclusion of words, phrases, sentences, or paragraphs into each category (Ander-Egg, 1980, 2003). The analysis was completed simultaneously by the first author and two judges who performed their analyses independently with a list of previously created categories. They also developed new thematic categories that emerged during the analysis but were not included in the initial list. The categories addressed situations in which participants felt stigmatized, consequences of their stigmatization, and ways in which they coped with this stigma. Afterward, all three analysts met and coded responses that they agreed to include in the final analysis. The analysis's reliability was established jointly between all judges. Selected passages from the text on which all analysts agreed were included in the final categories. Sections of text in which analysts disagreed required a discussion to reach an agreement. If an agreement was impossible, the selected text was discarded. This consensus-based dispute resolution procedure generated an interrater reliability of 100% (Miller, 2001).

## RESULTS

Participants' answers were organized thematically into five categories that demonstrated the manner in which AIDS stigma manifested itself through particular social relations. A description of these categories can be found in Table 1. In this section, direct quotes<sup>1</sup> from the recorded sessions are presented to describe the themes. We present data for the five categories that embody the difficulties and consequences imposed by AIDS stigma on specific social relations with family members, friends, sexual partners, coworkers, and health professionals. Each quote ends with a code to identify the participant who verbalized it according to the recruitment groups representative of the most common means of infection on the Island: unclean needle sharing during injected drug use (MIDU = male; FIDU = female), unprotected heterosexual relations (HET), and unprotected homosexual relations (HOM).

### Stigma and Family Members

Participants informed that AIDS stigma was particularly evident in their relations with family members. Some of those stigmatization experiences led them to feel rejected by others or to practice self-imposed isolation to avoid tense interactions. The experience of living with HIV/AIDS became a family secret or some sort of rumor that everyone knows but would rather not discuss. As a consequence of these family tensions, some participants expressed that they felt others segregated them



**TABLE 1: Description of Content Analysis Categories**

<i>Category</i>	<i>Description</i>
Stigma and family members	All verbalizations of stigma experiences with immediate and extended family members and/or partner's family
Stigma and friends	All verbalizations of stigma experiences with friends described as having close relationships or others whose contact was less frequent
Stigma and sexual partners	All verbalizations of stigma experiences with sexual partners, in long-lasting relationships and casual encounters
Stigma and coworkers	All verbalizations of stigma experiences with coworkers with whom participants had close relations and others whose contact was less frequent
Stigma and health professionals	All verbalizations of stigma experiences with all types of health professionals, such as physicians, nurses, social workers, and psychologists

to the extent of banishing them from their home. Two participants<sup>2</sup> described such situations:

The first thing was that when I went home to eat they gave me a separate plate, spoon, and glass. It is there when I felt rejected by my own family. My own mother, because she is my mother! If I go to sleep at the house, I sleep with the dogs on the porch. They lock me out, give me a bowl, and I use it to relieve myself. To live like that, I prefer to go to a public restroom. I can use the restroom, but when I go to sleep late at night, they don't let me in the house. They leave me on the front porch, like a dog. (MIDU)

She is afraid when I kiss her and turns her face away. When I need more love is when she loathes me the most. She doesn't want to know about me. She is even selling the house to move to Orlando to avoid being near me. She says she won't tell me the address or phone number; she doesn't want to hear from me. (FIDU)

Social interaction with family members became particularly difficult when they started to show bodily signs of deterioration due to their condition. These signs placed strains in the process of establishing effective communication patterns with others. These patterns were also affected by instances of sickness that might have been unrelated to HIV/AIDS, such as common colds that were interpreted as signs of potential infection or imminent death. Two participants explained,

Indirectly yes, because I used to visit more frequently. I do not live with my parents, and visiting frequently with these bodily changes has limited me. Visiting less frequently so sometimes they don't see me, or that I may be having a secondary effect, not telling them things. I have let time pass, when I should have been making the most of it. Due to the condition, to the fact that they see you changing, in that sense it has affected me. (HOM)

It hasn't been easy for them. Each one reacted differently. The eighteen-year-old has created a barrier between us because she doesn't want to talk about the subject. If I get sick she doesn't want to come close; she is fearful and doesn't want to face the situation. (HET)

Some participants mentioned that they preferred not to discuss the matter with family members. Particularly alarming was the idea that even in families where

more than one member was living with HIV/AIDS, discrimination and ostracism occurred among them because of stigmatizing notions regarding their means of infection. With regards to means of infection, one participant told us,

Yes, it has affected my [family relations]. When my family found out about my HIV, my brothers stopped speaking to me. At least two of them to this day do not speak to me. So, I feel it was a bit negative since we had very good communication. Even with both . . . both of them, one of them is positive just like myself. He understands that his HIV is different from mine because his is not because of sex with men. (HOM)

Furthermore, they mentioned feeling rejected by their partner's family once they found out about their condition. The idea that they would infect a family member eliminated all possibility of positive relations with their extended family and affected their intimate life with their partner. One man in our study stated,

Afterwards, his parents found out about the situation and blamed me. Since he was younger than me . . . they blamed, persecuted, and even threatened me with taking me to court. They started screaming it to the wind, making people believe that their son was a victim of circumstance and that I was a seductive man looking for victims to infect. (HOM)

### Stigma and Friends

Participants said they felt stigmatized by their friends when they became aware of their condition. Stigmatization was manifested at times through open rejection and an abrupt ending of the relationship. On the other hand, other friends preferred to end the relationship silently and systematically by avoiding further social contacts. One participant told us,

Yes, because many friends give you the cold shoulder. They do not want to be with you. They avoid you and think you can infect them. (MIDU)

Social relations with friends were damaged by knowledge of the person's serostatus due to perceived feelings of pity, rumors as to their deteriorating health, and physical changes related to the onset of the condition that gave evidence of their infection. Some felt that they were constantly being associated with imminent death and infection, and therefore were abandoned by acquaintances. Furthermore, they expressed concern regarding comparisons their friends made between the way they looked before and after their condition was physically evident. For example, one participant said,

On the other hand, I had people telling me. . . . They reminded me of another time in my life and looked at me . . . and said, "Poor guy, you were so beautiful then. . . . Poor guy, you are now a shadow of what you used to be." Some people were very direct and said, "You look like a cadaver, you are really fucked." (HOM)

The idea that death was creeping up on them made social interaction with friends particularly difficult and stigmatizing, specifically the notion that any further investment in the relationship was futile, as it would end at any given time because of the death of the participant. One of them stated,

My friends, those I thought were my friends, have simply disappeared. No explanations, because they did not face me. Only one faced me and told me that he didn't want to be there when I died. I said, "Well, enjoy me while I'm here." But he did not return. . . . In my opinion, just cheap excuses. (HOM)

One issue that was present and described as important during the interviews was the disclosure of participants' serostatus. Some feared revealing such information to friends. Others had friends who recommended that they not reveal such sensitive information to other people to avoid stigma. The following participants manifested such worries:

Yes. Sometimes my friends say, "Don't tell everybody you have that because they will reject you. People are ignorant." (HET)

What happens with my friends is that I can tell almost nobody that I have this condition. I don't tell my friends that I have the condition because if I tell them they don't understand. I don't know how they are going to react and in order to avoid that . . . (FIDU)

No. They don't know. Only my partner. I haven't told anybody. Two or three of my friends who are also patients know. Besides them, none of my friends know. (HOM)

### Stigma and Sexual Partners

Participants expressed experiencing stigma in their interaction with sexual partners or love interests. They informed of feeling rejected by their sexual partners at the time they found out about their serostatus and by others they met afterward. Three participants told us,

Yes, my love life . . . the ladies. I am a man . . . and I like the ladies, with all due respect, but I can't wait [to tell her] once I'm there. Because I am, in other words, killing and harming that person. Then, if I tell that person the truth and she rejects me, how will that make me feel? You tell some people and they understand. They say, "At least he was sincere, let's give him a chance." But there are others that don't. (MIDU)

Definitely yes. For example, my relationship with my partner was affected to the point that we did not continue . . . we left each other. Although he supposedly understood at the beginning; at one point it affected him and we left each other. (HOM)

It's not the same as before. I had my relationships and was relaxed; not now. If I find someone that I am interested in, when I tell them it all ends. It's really hard. (FIDU)

Participants reported that their partners expressed constant concern and anxiety over the possibility of infection to the point of denying the possibility of sexual intercourse. Feelings of persecution as potential vectors of infection led some participants to assume that their sex lives were over. Two participants mentioned,

I am afraid that even with condoms I might infect them. Psychologically, I have lost the appetite . . . my sexual appetite. (FIDU)

I know a person who is interested in me but doesn't have the condition. Sometimes I avoid establishing relationships with another person. I avoid it, and I am a young

person. I am not ugly. I may not be the last Coke bottle in the desert, but I am not ugly. (HET)

One of the most worrisome findings regarding stigma among sexual partners was the fact that in some instances, this rejection was accompanied by threats of physical violence if the seronegative partner were to become infected. One woman mentioned,

My husband argues with me and says "If I become positive, you'll see." He threatens me. (HET)

### Stigma and Coworkers

Social relations in work settings were also influenced by stigma. Some participants related that rumors of their health status started spreading in their workplace. Some coworkers asked them directly, whereas others simply stopped interacting with them. In more severe instances, some people openly manifested stigmatization through segregation or by being relocated to another job. One participant explained,

When I started showing my first physiological traits of the condition; losing weight, chronic diarrhea. Obviously some of my friends were part of my work setting. Some people started sharing information in which confidentiality was completely broken. I had sat with them and told them "Look, this is happening to me but don't tell anyone until I am ready to deal with this situation." They would tell me "No problem, this is between us." But, when I arrived at work everyone was looking at me and they already knew. . . . Sometimes new positions would be available, I would be nominated and then left out. . . . In terms of employment all doors were closed to me, I was suddenly on the street. (HOM)

One situation particular to their interaction with coworkers was that participants had difficulty identifying whether the situations they were facing were caused by stigma. They described discriminatory practices in these settings as subtle, and it was evident that at times, participants were unable to identify them effectively. Two participants mentioned,

I was working at a [fast food restaurant] and the manager found out from somebody that also worked there. I wasn't discriminated against at work, but I was taken out of the kitchen. I used to make hamburgers, salads, and other things. I saw that after someone made a comment I was taken out of the kitchen and into the eating area. I quit. (MIDU)

I used to prepare lunch at a preschool. One of the mothers asked me to work at her house from 4 to 7 p.m. taking care of her children. . . . When she found out I was HIV positive she immediately told me that financial matters at her house were bad and that her husband decided they didn't need my services any longer. They were people with money. (HET)

One of the most significant consequences of stigma in the work scenario was the inability to find work. Furthermore, due to previous stigmatizing experiences some participants understood that they would be unable to find work in the near future. Three participants told us,

I haven't been able to find work in cafeterias . . . or anything like that. (FIDU)

Yes, if I tell them what I have I will not be employed. Anyway, I can't do what I did before because ten years ago I was stronger than now. Now I am weak. I get tired easily. My production would be slower. (HET)

Before, I could work. I can't work now because the government asks for your health certificate, you know? (FIDU)

### Stigma and Health Professionals

One final example of the difficulties that stigma poses to healthy social relations was its effects on interactions with professionals in health-related fields. Refusal of health services was one of the most stigmatizing situations faced by participants. Two participants mentioned,

Yes, it happened to me once. I went to a dentist in Canóvanas [town] and after they sat me in the chair and the technician started to ask for my data, she asked me if I had any conditions. I told her that I was HIV positive and she refused to see me. She went and spoke to the dentist and told me "We can't see you." (HET)

I have gone to the emergency room at [a local hospital] and as soon as I go in they ignore me. I walk up to them and say "Excuse me," and they ignore me. Or, when I go in they immediately say "What do you want? What do you want?" . . . That's what has happened to me. Yes, that is discrimination, that is discrimination. To openly discriminate. (MIDU)

Other consequences participants faced when confronted with stigmatizing attitudes from health professionals were lack of effective communication and the need to self-medicate. Not all manifestations of stigma resulted in denial of services. Still, some informed that the quality of services diminished. Three participants mentioned,

Yes, as I said before, when I was hospitalized I felt rejected by nurses. Not by doctors because they come, see you and leave. The nurses that are tending to you right there, you generally see the rejection, the fear, the lack of treatment and attention. (HOM)

They show it [behaving] like robots. Like people who are robots. They put your IV and that's it. It's not because they want to help a person, it is an automatic thing that they have to do and they do it. (FIDU)

Since I became HIV positive I don't like visiting doctors or hospitals. I would like to not have to come here. I don't like people talking to me about the subject. I segregate myself. Do you know why? To forget that I am HIV positive. . . . I'd rather go to the pharmacy to buy anything and take it. At least I know what my ailment is . . . and what to buy. I go to the pharmacy and buy it. I don't come here for a prescription or to an emergency room. (HET)

Although some stigmatization by health professionals seemed to be overt and explicit, in other instances, it was described as subtle and was perceived through body language and the avoidance of interaction. Furthermore, some people avoided revealing their serostatus for fear of rejection by these professionals. One participant reported,

It's a subtle discrimination, it's not that they won't see you, but it's a way of not being authentic with the patient. I see a lot of that, especially when they [the patients] are ignorant . . . for example, a drug addict, a prostitute, or someone with no education. (HOM)

One particularly troublesome finding was that some people hid their serostatus from their service providers to receive better services. Although it is the patient's right to withhold such information, in some cases disclosure of one's HIV status is vital to receive adequate care. One participant stated,

I still go to emergency rooms and don't say I am HIV positive unless . . . unless I see that what I have is really due to my condition, that it is not another routine thing. (HET)

## DISCUSSION

Our data demonstrate the importance of social interaction in the stigmatization process. As outlined in Goffman's (1963) stigma framework, HIV/AIDS has become an attribute that contributes to devaluing PLWHA. Furthermore, social interaction between the stigmatized (in this case, the seropositive) and the stigmatizer is a difficult process in light of the negative characterization of PLWHA. Although many interpretations arise from participants' quotes, we would like to discuss four areas that we feel are particularly salient for the development of future research on the implications of AIDS stigma on social interaction and interventions to address it.

### Important Relations in the Puerto Rican Context

One of the most interesting results of this study was that when asked about strained relations, participants initially always mentioned stigma within their families. We believe that this fact, which some might interpret as a methodological issue, is linked specifically to Puerto Rican culture and its professed values. Social interaction is a vital dimension to address when describing "how Puerto Ricans are". Beyond stereotypical beliefs (promulgated to increase tourism) describing all Islanders as welcoming and helpful to other people, Puerto Ricans place a great deal of value on their social relations. Families and friends (who are frequently described as "extended family") are sources of support in many aspects of our daily life.

Being part of a family and the support it entails is valued highly in the Puerto Rican culture. This idea has been coined as *familismo* and is used to describe a tendency among Latinos and Latinas to view families as the most important source of support (Marín, 1989). *Familismo* entails "interdependence, affiliation, and cooperation" among family members (Parés-Avila & Montano-López, 1994, p. 343). Past research has recognized the need to incorporate family dynamics into HIV/AIDS-related research with Puerto Ricans (Rivera-Ortiz, Nieves-Rosa, Ortiz-Torres, & Rosado-González, 2004). This should not be surprising, as HIV research has shown that Puerto Ricans assign great importance to family relations (Díaz, 1998). For example, family members are a strong source of social support when dealing with the consequences of HIV/AIDS (VanOss-Marín, 2003). This support is expressed in the context of the family unit as an unvarying source of support (Bravo,

Canino, Rubio-Stipec, & Serrano-García, 1991; Bravo Vick, 1989). However, social values such as *machismo* (traditional gender roles assigned to men), sexism, and homophobia, which are intertwined with and coexist in AIDS stigma, are also strongly encouraged and taught as part of family dynamics (De La Cancela, 1986, Ortiz-Torres, Serrano-García, & Torres-Burgos, 2000). Therefore, the family unit can be simultaneously a scenario for support and a place in which stigmas are expressed. Still, because of the social value attached to the family in this cultural context, excluding oneself from social interaction with its members is almost impossible, even when stigmatization is present (Varas-Díaz, Serrano-García, & Toro-Alfonso, 2004).

Feeling stigmatized by family members was a particularly difficult and frequent experience for participants. This situation is worrisome, because it eliminates family members as potential sources of support to address the consequences of living with HIV/AIDS. Acknowledging the potentially positive role that social support has on physical and mental health and the importance of the family unit in this cultural context, stigmatization by families can be particularly damaging to Puerto Ricans living with HIV/AIDS (Fasce, 2001; Hays, Turner, & Coates, 1992; Kimberly & Serovich, 1996, 1999).

Similar issues are encompassed in relations with friends and sexual partners. When families become sources of stigmatization, friends or "extended families" can serve as alternate providers of support and sharers of ideas and beliefs (García, 1998). Nevertheless, these were also identified as people who frequently stigmatize. Stigmatization by these individuals was described as particularly hurtful. Because of the value placed on sincerity in these social interactions and relations, friends and sexual partners tended to be harsh with PLWHA when expressing their opinions or concerns. Participants stated that verbal stigmatization was most common from friends. On the other hand, they mentioned that their sexual partners feared them because of the possibility of infection. This fear could turn to lack of support and rejection in their most intimate relations.

### Physical Changes

Another important finding of this study is the body's key role in the stigmatization process. Previous research has addressed the issue of the social meanings attributed to the bodies of PLWHA (Das, 2001; Murphy, 1995; Sontag, 1990). Particularly evident in our results was the role the body plays in social interactions and stigmatization once it starts to change because of HIV/AIDS. Participants informed us that the beginning of a bodily deterioration process associated with HIV or the secondary effects of treatment fostered stigmatization, as people associated these changes with prolonged illness and imminent death.

This bodily dimension of stigma in social interaction must be addressed further in research exploring the consequences of antiretroviral therapies. Common consequences such as "wasting" and lipodystrophy are evident body changes associated with treatment (Kalichman, 1998b). As more people engage in long-term treatment, these manifestations can foster stigmatization in social interaction and therefore have negative consequences on health.

### Ending or Continuing Social Interaction

Participants informed that stigmatization led some people to stop interacting with them. Although ending social relations with families and friends can be hurtful, the manner in which this occurred was particularly aggravating. For example, whereas some people simply decided to stop interacting with participants, others kept doing so in a lengthy process mediated by social distance, avoidance, and a subtle fear of infection. Although abrupt endings to relationships can have negative consequences, worse implications might arise from constant and ongoing stigmatization processes that last undetermined periods of time.

Participants described both types of situations but provided more detailed descriptions of stigmatization by those people with whom they continued to interact, even when stigmatization was present. Such was the case with family and friends. These relations in some cases are socially constructed as “unbreakable” relations from which participants cannot escape, even when ending them might be desirable. This situation exposes PLWHA to continuous stigmatization.

### Structural Implications of Damaged Social Interactions

As we mentioned in the introduction to this article, stigmatization in social interaction has individual and structural consequences. Some of the latter consequences are described by participants, particularly in relation to their work settings and access to health services. For example, when stigma was present in their interactions with coworkers, they were unjustly relocated and, in some cases, fired. The same was found in health settings and in their relations with health professionals. People felt unwelcome in health settings and were unable to develop trusting relations with health care providers that stigmatized them. These results point to the importance of understanding how stigmatization in social interaction can foster negative structural consequences for PLWHA. In this case, job loss and poor access to health services are prime examples. These, in turn, can lead to further physical and mental health deterioration.

One of the main issues to address regarding the structural implications of stigma is the institutionalization of stigmatization in health settings. Some participants expected to be treated differently regardless of where they received services because of health professionals' reactions on knowing of their HIV status. This is consistent with research stating that treating patients differently in these scenarios is “legitimate” because of people's perceptions of the accuracy and truthfulness of their negative beliefs regarding the sick (Whitehead, Mason, Carlisle, & Watkins, 2001). This institutionalized stigmatization has consequences on the daily lives of Puerto Ricans living with HIV/AIDS, such as avoiding health service settings and self-medicating. This is another example of how social interactions are mediated by the structural implications of stigma and, in turn, have detrimental effects on people's lives (PAHO, 2003).

Our results demonstrate the continuous existence of AIDS stigma faced by PLWHA in Puerto Rico. Furthermore, they point to the need for better understanding of the key role social interactions play in the stigmatization process to address it effectively through research and intervention development. In light of these findings, we propose that (a) more research be carried out with the Latino community in



general, and with Latino families in particular, to assess the stigmatization faced by PLWHA; (b) research be translated into intervention development to reduce stigma among people interacting with those living with HIV/AIDS; and (c) future stigma research on the role of social interaction further explore the structural consequences of stigma and the public policies needed to counter them.

Even though more research on AIDS stigma is urgently needed, intervention development must be a priority to address effectively its consequences in the lives of PLWHA. These interventions must focus on (a) stigmatizing family dynamics, which might limit the amount of social support that PLWHA receive taking into consideration the importance of the family in the Puerto Rican culture; (b) the role of stigma in delaying access to effective treatment because of the patients' fear of being negatively judged by health care providers; (c) the dissemination of information on AIDS stigma to coworkers of PLWHA to avoid stigmatization in the workplace; and (d) the integration of the subject of stigma in interventions geared toward sero-discordant couples and its consequences on their sexuality and other aspects of their daily lives.

These recommendations for future research and intervention development are but a small part of the many efforts that must be developed to combat AIDS stigma and its consequences. These challenges lie ahead for professionals involved in HIV/AIDS and stigma research. The need to address them is vital, and the urgency to do so is critical.

## NOTES

1. These quotes were translated by the authors, as the in-depth interviews were carried out in Spanish.

2. More participants described situations of stigma for each category. Due to issues of length in journal articles, only selected passages are presented. Contact the authors for further findings.

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