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My Body, My Stigma: Body Interpretations in a Sample of People Living with HIV/AIDS in Puerto Rico

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Abstract

AIDS related stigma continues to impact the lives of People Living With HIV/AIDS (PLWHA) negatively. Although the consequences of stigmatization have been widely documented, certain areas of study need to be further addressed in order to better understand their implications for PLWHA; such is the case of the perceptions of the body's role in AIDS stigma. A qualitative study was implemented including 30 in-depth interviews of PLWHA in Puerto Rico in order to explore their perceptions of the body's role in the process of stigmatization. Results include: participants' perceptions on how their bodies evidence their serostatus, description of past body marks, personal experiences with body marks, meanings attributed to their bodies with HIV/AIDS, and personal criteria used to describe the perfect body. These issues are described in the context of the social stigma faced by PLWHA in Puerto Rico and individual perceptions of the body's role in the process of self-stigmatization. Recommendations for intervention and research are described.

Keywords

HIV/AIDS, Stigma, Body, and Puerto Ricans

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My Body, My Stigma: Body Interpretations in a Sample of People Living with HIV/AIDS in Puerto Rico.¹

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AIDS related stigma continues to impact the lives of “People Living With HIV/AIDS” (PLWHA) negatively. Although the consequences of stigmatization have been widely documented, certain areas of study need to be further addressed in order to better understand their implications for PLWHA; such is the case of the perceptions of the body’s role in AIDS stigma. A qualitative study was implemented including 30 in-depth interviews of PLWHA in Puerto Rico in order to explore their perceptions of the body’s role in the process of stigmatization. Results include: participants’ perceptions on how their bodies evidence their serostatus, description of past body marks, personal experiences with body marks, meanings attributed to their bodies with HIV/AIDS, and personal criteria used to describe the perfect body. These issues are described in the context of the social stigma faced by PLWHA in Puerto Rico and individual perceptions of body’s role in the process of self-stigmatization. Recommendations for intervention and research are described. Key Words: HIV/AIDS, Stigma, Body, and Puerto Ricans

The HIV/AIDS pandemic can be described as one plagued by social meaning. More than twenty years into the epidemic it is evident that we are not only dealing with the biological effects of a virus; we are also facing the negative social meanings attributed to HIV/AIDS and the people who live with it. These negative socially shared meanings ascribed to the epidemic have been described as AIDS stigma and its consequences are disastrous for people living with HIV/AIDS (PLWHA) as they entail depression, denial of health services, and ostracism, among others (Herek & Glunt, 1988). Further research needs to be carried out in areas that are of significance for PLWHA and that have been neglected by AIDS stigma researchers. Such is the case of the body’s role in AIDS stigma (Chapman, 1998). Due to the evident biological dimensions of HIV for the body, the latter is seldom addressed when elaborating on the social dimensions of the epidemic; even when the body is also a social phenomenon.

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What is Stigma?

The concept of stigma dates to ancient Greece and was used to describe people with bodily marks or tattoos which evidenced their involvement in a bad deed and were therefore to be avoided (Crawford, 1996). The concept has also been defined as an unnatural mark on the bodies of saints, a mark made with a hot iron on the flesh of slaves, a bad reputation, and even a physical dysfunction (Real Academia Española, 1984). Other authors have described stigma as a social construction associated with the recognition of a difference, based on a specific characteristic, which is used to devalue the person who possesses it (Dovido, Major, & Crocker, 2000). All of these definitions share the idea that a stigma is the negative evaluation of a particular difference that may be associated with a person.

One of the most widely recognized conceptual frameworks on the subject was developed by sociologist Erving Goffman (1963). He defined stigma as a profoundly discreditable attribute, which could lead a person to be deemed almost inhuman. He identified three types of stigma: abominations of the body, blemishes of individual character, and tribal stigmas. Abominations of the body were described as 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 were stigmas associated with a person's character, identity, or simply their 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 referred to the negative evaluation of particular persons due to their association with a group. Some of these stigmas are related to race, ethnicity, and sexual preference. According to Goffman, all of these types of stigmas contribute to devaluing people. Goffman's definition is particularly important to understand AIDS stigma since PLWHA can encompass all three: abominations of the body (wasting syndrome), blemishes of individual character (responsibility over infection), and tribal stigmas (notions attributed to homosexuals as a group).

Other authors have expanded Goffman's (1963) framework by describing multiple dimensions of stigma (Jones et al., 1984). These include: concealability, course (of the stigmatizing condition), disruptiveness, aesthetic qualities, origin, and peril. According to these dimensions a stigma will have more negative effects if it is not concealable (therefore evident to others), if it is perceived as advanced in its course (such as an illness in its final stages), if it disrupts or hinders social interaction, if it is not beautiful or aesthetically pleasing to the observer, if the stigmatized person or group is blamed for its origin, and if it is associated with death.

Goffman (1963) stressed the importance of visibility of the stigmatizing attribute, and therefore its bodily dimension. According to him persons whose stigmatizing mark is clearly visible will be discredited by others, while those whose stigma is not visible are considered discreditable, since the possibility of being identified as stigma bearers is always imminent in social relationships. This possibility of being identified as a stigma bearer evidences the complexity through which those that are stigmatized must engage in on a daily basis, in order to avoid social interactions through which their marks may be identified. Daily life becomes a "hide and seek" game in which the outcome can be truly devastating.

The Body's Role in Stigmatization

One of the most relevant aspects of Goffman's (1963) conceptual framework to this current investigation is the body's central role in it. The body, as a biological and social entity, sets boundaries for particular types of stigmas.

Although more evident in some cases than others, the body plays a central role in the types of stigma Goffman (1963) identified. The most obvious are probably abominations of the body in which particular deformations or missing body parts elicit stigmatizing attitudes. Stigmas associated with blemishes of individual character also entail bodily dimensions. For example, this type of stigma can be found in an imprisoned person whose reality lies behind bars and whose bodily freedom is restricted due to a transgression of social norms. This transgression in turn may be interpreted as a fault of his/her character or personal identity. The same can be said about drug users whose bodies evidence their addiction either by physical marks of drug injection or by lack of bodily control under the influence of drugs (Capitano & Herek, 1999). Finally, tribal stigmas also evoke the body since they serve as identifiers of members of a particular group. This occurs through skin color, tattoos, body modification (Featherstone, 2000), or other types of marks such as those of a particular sickness.

These examples highlight the body's role in the stigmatization process. The importance of this role increases when the body is afflicted by a disease that is considered degenerative and deadly. Such is the case of HIV/AIDS.

Living in a Body with HIV/AIDS

Since the body is our vehicle for interaction with the world and others, it is through it that people experience the HIV epidemic. In this sense, the body cannot be separated from the experience of "living" with HIV/AIDS. People are exposed to infection through their bodies. In social interactions, in which bodies are embedded, the consequences of infection and subsequent stigmatization are evidenced.

Goffman's (1963) conceptual framework facilitates understanding the stigma that surrounds HIV/AIDS, and particularly of the body's role in such stigma. For example, PLWHA can encompass all three types of stigma identified by Goffman. They are perceived as having *abominations of the body* when they have visible marks associated with their condition, they suffer from *blemishes of individual character* when they are perceived as responsible for their HIV/AIDS status, and are victims of *tribal stigmas* when they are described as part of a "risk group". The same can be said for the multiple dimensions of stigma defined by Jones et al. (1984). Since HIV/AIDS may not be concealable in some cases, it may disrupt social interactions with those who are afraid of contagion, and since it is associated with death PLWHA are very likely to be stigmatized. Since stigmatizing attitudes may be difficult to hide for the stigmatizer, they can make it harder, or even impossible to interact with PLWHA. This is particularly plausible when the marks that foster stigmatization are evident and clearly visible.

The role of the body living with HIV/AIDS in the stigmatization process can be dual: (1) it can provide physical or visual evidence of the condition; described by Goffman (1963) as the "discredited" or (2) can work as a generator of self-stigmatizing attitudes even when the condition is not clearly visible to others (described by Goffman

as the “discreditable”). Evidence of the condition arises from bodily marks. Some of these include, but are not limited to, lesions, skin infections, fungus, and rashes (Murphy, 1995). Other health complications such as lipodystrophy, the condition in which fat is disproportionately accumulated throughout the body, can serve as markers of the disease (Velenti, 2001). Its consequences entail accumulation of abdominal fat and the development of a “buffalo hump” in the top part of the back. The same can be said of wasting in which the individual is physically debilitated due to loss of body fat and muscle tone (Kalichman, 1998a). This wasting is manifested in loss of mass in the cheeks and gluteal muscles. Although some of these changes can happen to people with other health conditions, for PLWHA they entail other meanings due to the social stigma attached to the infection.

On the other hand, the second manifestation mentioned above refers to asymptomatic people who can internalize negative perceptions widely held throughout society regarding their infected bodies. This is not surprising considering that the HIV/AIDS body has been conceptualized as a site of death and contagion, an instance of prejudice, an entity suspended between health and sickness, and as an entity that succumbs as it faces the epidemic (Chapman, 2000; Murphy, 1995; Waldby, 1996). People living with HIV/AIDS are acutely aware of these interpretations, and in some cases may hold them to be true (Varas-Díaz, 2002; Varas-Díaz, Serrano-García, & Toro-Alfonso, 2004).

This stigmatized body living with HIV/AIDS must not be considered a natural or given phenomenon. On the contrary, it is a socially constructed body that lives within collectively created discourses of stigmatization. It provides evidence to others, and to themselves, that the stigmatization process can be continuous and imminent. When this process occurs, its consequences can be dire.

The Consequences of AIDS Stigma

The magnitude of the stigma surrounding HIV/AIDS is reflected in the coining of the term “AIDS-related stigma” or “AIDS stigma” (Herek & Glunt, 1988, pg. 886). The myths that surround the HIV/AIDS epidemic contribute to this stigmatizing process (Cunningham & Ramos-Bellido, 1991). Among the social meanings attributed to the epidemic we find that HIV+ 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 not contributing to society’s development.

Research has 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, lack of sexual activity, 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).

AIDS stigma researchers have barely begun to tap the surface on the implications of the body living with HIV/AIDS. Nevertheless, some published research has documented that PLWHA who suffer from lipodystrophy can suffer from bodily discomfort, low self-esteem, and depression (Power, Tate, McGill, & Taylor, 2003). These negative consequences foster social isolation in people who feel self-conscious about their bodies due to HIV infection and therefore avoid social interaction (Tate & George, 2001). In such cases the body with HIV/AIDS contributes to feelings of stigmatization from society in general and, in the worst cases, to self-stigmatization (Chapman, 1998).

The potential social exclusion and discrimination associated with AIDS stigma evidences the need to address its consequences on social interactions with different people, particularly, those consequences that may arise from feeling stigmatized in relations that are important to PLWHA. Researchers still need to carefully address the role of the body in the lives of PLWHA since it can be a vehicle for social, and personal, stigmatization. Those people who are important to the lives of PLWHA can identify body changes, particularly if they interact with them on a regular basis. These include family members, sexual partners, and personnel in health scenarios who are trained to examine the body for signs of sickness.

The HIV/AIDS Epidemic in Puerto Rico

Examining AIDS related stigma, and the role of the body in its process, is particularly urgent in Puerto Rico. The HIV/AIDS epidemic has severely impacted the Island and the numbers of reported AIDS cases are alarming. Out of the more than 29,205 reported cases of AIDS, 18,370 have already died (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 (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 of the epidemic in the world (PAHO, 2001; World Bank, 2001) after Sub-Saharan Africa. To make this scenario even worse, HIV cases were not reported until 1999 and seroprevalence data is unavailable at this time (Sosa Pascual, 2003).

Just as in many other countries around the world, these numbers are just one face of the epidemic. Research has shown that PLWHA in Puerto Rico face stigma on a daily basis (Santiago, 1998; Varas-Díaz, Serrano-García, Toro-Alfonso, 2004; Vargas DeLeón, 1996). Some of the research documenting this stigma, as recently as this decade, reports difficulties accessing health services, ostracism, and open discrimination by families, friends, sexual partners, and employers (Kaiser Family Foundation, 2001; Porbén, Torres Burgos, & Bernal, 2000; Torres Burgos, Porbén, & Bernal, 2000; Varas-Díaz, 2002). In this context, research concerning stigma's manifestations in the lives of PLWHA is essential to address the epidemic.

As researchers engaged in a qualitative study we would like to address the issue of context before describing the implemented method. Our lives have been touched by friends and colleagues affected by this epidemic. We have incorporated HIV into our research agenda in order to contribute to the development of knowledge that can better

serve to enhance the quality of life of PLWHA in Puerto Rico. Although some people may understand that the HIV epidemic is over, we interpret such a notion as yet another manifestation of stigma. An epidemic that is “over” needs no attention for prevention, entails no discussions of subject matters that make some feel uncomfortable (such as sexuality and drug use), and keeps HIV/AIDS as a sickness of “others” who engage in “risky lifestyles different from ours”. We hope that this research is a step in the right direction and that it may contribute to a better understanding of the consequences of the epidemic in Puerto Rico.

In order to address these concerns, the main objective of this study was to explore the role of the body in the stigmatization of PLWHA in Puerto Rico. In order to achieve this objective we explored the following research questions: (a) Do PLWHA feel their bodies evidence their HIV infection?; (b) Have people had body marks in the past that may evidence their HIV infection?; (c) What experiences have PLWHA had with body marks?; (d) What meanings do PLWHA attribute to their bodies?; and (e) What elements do PLWHA take into consideration when describing the perfect body? These questions emanated from conversations with PLWHA through intervention work in community based agencies who participated in workshops we have offered throughout Puerto Rico.

Method

Due to the exploratory nature of this research, its novelty in the Puerto Rican context, and the literature review (Herek et al., 1998), we developed a qualitative method. Few studies on AIDS stigma have been carried out in Puerto Rico and those that do exist have mainly been case studies. Therefore, we decided to implement a qualitative design that would enable us to better understand the manifestations of AIDS stigma in great detail; particularly participants’ body perceptions as they relate to AIDS stigma. Research objectives were addressed through in-depth interviews carried out with PLWHA. We chose this technique due to the difficulty that participants might face when asked about their personal health, stigma experiences, and body changes in front of other people, such as in focus group discussions. We understood that individual interviews provided a more secure and ethical environment for participants to manifest their worries, concerns, and negative experiences.

Participants

The sample consisted of 30 Puerto Ricans living with HIV/AIDS. These participants met the following criteria: Puerto Rican nationality, adults (at least 21 years of age), receive the services of an HIV/AIDS community based organization (CBO), knowledgeable of the way they were infected, and having felt stigmatized due to their condition. These criteria allowed us to: (a) control for one particular stigma combination that is commonly manifested in Puerto Rico; that is directed towards immigrants from the Dominican Republic, (b) have all participants be consenting adults, (c) facilitate their recruitment in organized HIV related agencies, (d) know of their mean of infection, and (e) enable participants to speak on personal stigma experiences.

The 30 persons who participated in the in-depth semi-structured interviews were divided in groups of ten according to the most common contagion categories in Puerto

Rico. These are unclean needle sharing for 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 since each of the categories elicits different value judgments from society and yields different stigmatizing experiences (Baez, 1999; Kalichman, 1998b). For example, drug use and homosexuality are widely stigmatized in our context but for different reasons (e.g., the first may be more associated to sickness and the second to a character flaw). Therefore, these subdivisions allowed us to gather stigmatizing experiences from people who face different manifestations of stigmatization. The group infected by needle sharing was composed of six men and four women in proportion to the incidence of infection by needle sharing in Puerto Rico as regards to gender (OCASET, 2004). The group infected by heterosexual relations was composed of women since they are the fastest growing group in the epidemic in Puerto Rico (OCASET, 2004) and research has shown particularly high levels of stigmatization among them (Santiago, 1998). Men were excluded from the heterosexual transmission group due to our desire to focus on women, since they are more stigmatized. Furthermore, we felt intervention development was a priority for them since they combine several types of stigma. Finally, the group infected by homosexual relations was composed of men since they have been widely stigmatized in the past and there are no statistics regarding HIV transmission among women who have sex with women in Puerto Rico. Participants were not informed of the study's stipend before they decided to participate in order to avoid any unintentional coercion. Although we asked them to inform us of their mean of infection, a situation that might have been uncomfortable for them, participants were always reminded that they could choose not to reveal such information, and not to participate in the study. We did not encounter such a situation since they routinely talked about the subject in the agencies through which they were recruited.

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%). Concerning sexual orientation 16 reported being heterosexuals (53.3%), 12 homosexuals (40%), and 2 bisexuals (6.7%). With regards to formal education, 14 people (46.7%) had completed high school and 6 a bachelors degree (20%). Most participants were unemployed (n=22, 73.3%) and their monthly income ranged from 0 to \$500 (n=16, 55.2%). Ten participants reported living alone (33.3%), 9 with family members (30%), 5 being homeless (16.7%), and 6 with other non-specified people (20%). Nineteen participants (63.3%) reported currently undergoing antiretroviral therapy. Ten were unaware of their viral load (33.3%) and 8 were informed it was undetectable (26.7%). The amount of time participants reported knowing of their infection ranged from 4 months to 20 years. We must stress that we did not intend to recruit a representative sample of the population of PLWHA in Puerto Rico. We included the means of infections as recruitment categories in order to have a more varied sample with diverse stigma experiences, but representativeness was not an aim of the sample selection process.

Participants were recruited from local community based organizations (CBOs) that have traditionally provided services to PLWHA in Puerto Rico. We met with key personnel from each agency prior to participants' recruitment to explain the study and subject participation. They identified potential participants within their organizations and

requested their participation in the study. CBO personnel contacted long time participants in their agencies, as well as people who had recently begun to receive their services. Participants completed a short screening questionnaire, administered by CBO personnel, to ensure that they complied with the selection criteria.

Instruments

Several instruments were used throughout the study. These included a screening questionnaire, demographic data questionnaire, in-depth interview guide, and a consent form. We developed all of these instruments in light of the recruitment criteria of the study, demographic data that was of interest to describe the sample and questions related to AIDS stigma that addressed the objectives of the study.

Screening Questionnaire

This instrument included questions related to inclusion criteria and contact information. These questions addressed participants' nationality, age, experience with HIV/AIDS services in a CBO, their means of contagion, and their stigmatization experiences. Since the concept of stigma may have been unknown to participants due to its academic nature, questions about stigma were phrased in a way which described the construct using key words addressing prejudice and exclusion. These questions were: (a) Have you ever felt people treat you differently because you live with HIV/AIDS? (b) Have you ever felt that people fear you because you live with HIV/AIDS? and (c) Have you ever felt that people have negative opinions of you because you live with HIV/AIDS? CBO personnel administered the instrument after being trained, and participants completed it in five minutes. Contact information gathered in the questionnaire was used to schedule interviews with participants who wished to do so at a later time, and confidentiality was assured by keeping the source of the call anonymous.

Demographic Data Questionnaire

The instrument included questions regarding participant's economic status, age, sex, gender, area of residence, education level, and HIV/AIDS indicators (e.g., CD4, viral load). Participants completed the questionnaire in a 10 minute period before the interview.

In-Depth Interview Guide²

The in-depth interview guide was composed of a list of 40 open-ended questions. These questions addressed several subjects: the personal experience of being HIV+, situations in which participants have felt stigmatized, and skills they possessed to cope with AIDS related stigma. It was developed in light of an extensive literature review on AIDS related stigma, its dimensions, and consequences. This interview guide ensured some level of uniformity among interviews which lasted an average of two hours.

² If the reader is interested in receiving a copy of sample questions used in the interview guide, he/she may contact the first author via email at nvaras@rrpac.upr.clu.edu.

Consent Form

Participants completed a consent form that informed them of the objectives of the proposed study, the nature of their participation including its duration, that their interviews would be audio-taped, possible risks and benefits of their participation, their option for ending their participation at any given time without being penalized, the possibility of requesting psychological services free of cost if they deemed it necessary, their right to receive a summary of the study's results, and the economic incentive they would receive for their participation. All participants discussed the consent form and its content with the interviewer before starting the interview.

Procedures

The study's protocol and consent form were submitted for evaluation to the University of Puerto Rico's Institutional Review Board (IRB). Once their approval was obtained the protocol, which started with instrument development, was implemented. Upon 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 the questions and structure of the guide. Afterwards, the guide was pilot tested by interviewing two PLWHA recruited from one of the aforementioned CBOs. Results from the pilot study evidenced the need to further simplify phrasing of the questions and the need to add others related to social relations with health professionals and their stigmatizing attitudes. For example participants initially did not understand questions related to potential difficulties when interacting with their doctors and nurses. Furthermore, questions addressing AIDS stigma in emergency rooms were incorporated.

After this information was incorporated, we re-contacted the CBOs and set a time to visit the agencies and meet privately with participants previously identified with the use of the screening questionnaire. People who wished to participate completed the consent form, the demographic data questionnaire, and participated in the audio-taped interview. Those who were identified by the CBOs as ineligible for participation (according to the screening questionnaire) were thanked for their interest and given informational materials on HIV/AIDS. Those who completed the interview were given a \$50 stipend.

The interviews were carried out by a team of four interviewers who were properly trained prior to interacting with participants. They completed eight hours of training on issues related to: (a) participant recruitment, (b) ethical issues, (c) interviewing techniques, (d) familiarization with the instruments, and (e) techniques to avoid priming participants for answers.

Data Analysis

The information gathered through the audio-taped in-depth interviews was transcribed, stored and analyzed with the use of the NUDIST N-VIVO software version 1.1. We carried out a content analysis and used the theme as our unit of analysis. It allowed 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 the help of a list of categories; developed in accordance to the interview guide and others that emanated from our reading of the transcribed interviews. While some categories addressed the specific issues that were asked of participants, others surpassed them. For example, upon an initial reading of the interview transcripts, several categories regarding difficulties when interacting with sexual partners were created. The preliminary independent analysis allowed the judges to develop categories that were present in the texts but surpassed those in the initial list. In order for a category to be included in the analysis, all judges had to agree that it was present in the interviews. Some of these categories addressed situations in which participants felt stigmatized, and the consequences of their stigmatization. Afterwards, all three analysts met and coded responses that they agreed to include in the final analysis. The analysis' reliability was established jointly between all judges. Selected passages from the text on which all analysts agreed were included in the final categories. For those sections of text in which analysts disagreed, a discussion was fostered to reach an agreement. If none was possible the selected text was not included in the final categories. This consensus-based dispute resolution procedure generated an inter-rater reliability of 100% (Miller, 2001). This step was carried out in order to ensure that the judges agreed in the final interpretation of the coded passages and to avoid the inclusion of verbalizations that were unclear in their phrasing and overall meaning.

We should also state that before the data analysis took place several steps were taken in order to ensure the trustworthiness of the data (Lincoln & Guba, 1985; Schwandt, 2001). These included: (a) supervising the overall methodology through systematic documentation of data collection and analysis agreements among the research team, (b) supervising all interviews once they were carried out and providing input on each interviewer's techniques, and (c) establishing group discussions after all interviews, so that interviewers could manifest their concerns and overall feelings regarding the data collection process. Furthermore, we presented the results to groups of PLWHA (some of the study's participants included) in order to receive their input regarding our analysis and they agreed with our interpretations of the data. We believe that these steps, along with the detailed analysis process, contributed to the quality of the data gathered and the results of the study.

Results

Participants' answers have been organized thematically into five categories which reflect participants' bodily interpretations once they knew of their change in serostatus (See Table 1). These include: the body as evidence of HIV/AIDS infection, past body marks, experiences with body marks, meanings attributed to their bodies, and criteria used to describe the perfect body. In this section, direct quotations³ from the recorded sessions are used to describe the themes and other important features of the responses. Each quotation ends with a code to identify the participant that verbalized it according to the recruitment groups representative of the most common means of infection in the Island: unclean needle sharing during injected drug use (MIDU=male; FIDU=female), unprotected heterosexual relations (HET), and unprotected homosexual relations (HOM).

³ These quotations were translated by the authors since the in-depth interviews were carried out in Spanish.

It is important to mention that during the interview process the subject of the body was brought up by participants before it was mentioned by the interviewers. The subject of the body was the last in our interview guide but participants included it in almost all aspects of the interview, evidencing its importance in understanding AIDS related stigma. We placed the subject of the body as last in our interview guide since we felt that it would be one of the most difficult subjects to address, due to the emotions that it may evoke.

Table 1

Description of Content Analysis Categories.

Category	Description
1. The body as evidence of HIV/AIDS infection	In this category we included all verbalizations addressing participants' perceptions of how their bodies evidenced to others their serostatus. It also included description of the specific marks that served as evidence of serostatus and activities undergone to avoid them.
2. Past body marks	In this category we included all verbalizations addressing body marks that participants reported having in the past, but not at the time of the interview. It also included past instances of stigmatization that emanated from those marks.
3. Experiences with body marks	In this category we included all verbalizations addressing how participants reacted to their own body marks related to their serostatus. Furthermore, we included experiences of social interaction with other people in which these marks fostered stigmatization.
4. Meanings attributed to the body	In this category we included all verbalizations addressing the meanings that participants ascribed to their bodies now that they were living with HIV/AIDS. The category includes negative and positive interpretations of their bodies.
5. Criteria used to describe the perfect body	In this category we included all verbalizations addressing the criteria that participants informed would be necessary for them to consider their bodies as being perfect. It includes issues related to HIV/AIDS and other aspects of their daily lives.

My Body as Evidence of HIV Infection... or is It?

Participants believed that their bodies evidenced their serostatus to others through visual marks caused by HIV/AIDS. Some of the marks described included consequences of the wasting syndrome, changes in the color of their skin, loss of muscular mass, and sores. Others, like diarrhea and loss of appetite, were described as marks that evidence HIV infection but were not visible to other people. Although described as invisible, they interpreted them as bodily marks due to the behavioral changes associated with them that could evidence their health status to other people.

For example, in my case I have been living with it for 20 years and the wasting in the face, maybe the wasting in my gluteus, my buttock. If the person is informed, he will know [I'm positive]. In my work setting the experts, researchers, must know about the secondary effects of the medications to know when a person is going to ask for services. HOM

Yes, lipodystrophy. It was caused by medications. The fact that one's cheeks dry up. One looks like a cadaver. You loose weight in all your body. On one occasion, a medication called Crixivan gave me a belly like Santa Claus, but that is not such a problem since there are a lot of big-bellied people around. But when you see a person today and the next day, you can see the bones and skin in his face, specifically in the face. I would say that the face... it's the biggest stigma faced by patients today. HOM

Other participants recognized that the body could evidence serostatus, but specified that theirs did not due to their asymptomatic status. Furthermore, some participants mentioned that those bodies that do evidence HIV infection do so due to lack of medical care and personal hygiene.

No. For example, nobody will notice by looking at me. Some people show it because they don't take care of themselves, visit doctors, or go to treatment. At least with me, nobody is a fortune-teller to say 'he has the condition' because I don't look like it. MIDU

No, because I take care of myself. Not by my appearance, although I don't have designer clothes or nothing like that. But look... I am taken care of and groomed. HET

I don't appear to have HIV because I am a drug addict. There are women who use drugs and are skinny and they don't have it. You get me? FIDU

Past Body Marks

Some participants reported that they had body marks in the past due to their serostatus, but that at the time of the interview they could identify none due to treatment. In the past, these marks led people to take an HIV test and to hide them from others. Therefore, they experienced social isolation as a consequence of hiding their body marks.

Well, it's had more to do with the redistribution of muscle mass. It hasn't been something significant because, as I mentioned, I have always been thin. But there was a time at the beginning of my therapy that I started to notice that all my fat would redistribute itself to my stomach. But not now, that has been solved and I am back to usual. HOM

Some of them (marks) on the skin. It is not that one rips pieces of flesh off. When one is gray like a cadaver, people look at you and know. That is

the face that people know of AIDS. Right now, I dress well, put on linen clothing, and my briefcase. Since I am into so many things right now... nobody knows that I am HIV, if I don't tell them. HET

Experiences with Body Marks

When asked about past experiences with body marks, participants mentioned personal interpretations of them and reactions from people who surround them. Once again, social isolation permeated these experiences since they avoided interacting with others who might ask about the origin of such marks. They also mentioned that having these marks negatively affected their mood states, establishing a mind-body connection regarding the consequences of body marks. On the other hand, some people reported that they decided to seek medical help once these marks were visible to others.

...I had bodily reactions. Suddenly all my skin was blemished. My life's rhythm had diminished. I could not move around in the same way. The neuropathy, lipodystrophy, and seeing myself with certain characteristics... I would look at myself in the mirror and not see the same person I used to be. The deterioration... HOM

Well, some people have asked me if I am running a lot, weight lifting or if I am losing my buttocks. What's wrong with me? They ask me if I had a bad night because of my face. If I am exposed to the sun... these black marks become more accentuated. It's not a thing of a day or two... they stay like that for weeks. HOM

...with the lipodystrophy people see you and it is stigmatizing because they know you have HIV. Therefore, what are you gonna do? You do what you have to do. I take the pills I have to take and then look normal and people...change from heaven to Earth. I have approached people, men that did not pay any attention to me when I had the lipodystrophy. After I treated my face with certain things they started to be interested. The image was erased, even knowing I was positive, and were attracted to me. Nothing more than physical appearance. There you can see the importance of appearance in these cases. HOM

When I was thin people said "Look at her, she's got AIDS. She is finished". FIDU

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

With HIV I am not normal, I become deformed in all ways. My face, body, everything. Obviously, when your face and body deform, your mind starts to deform because it starts to affect you. Many patients have lost their desire to live due to the rejection. That rejection is due to external appearance. I think nothing is being done with respects to that. HOM

Meanings Associated to the Body with HIV/AIDS

Participants reported different meanings associated with living in a body with HIV/AIDS. Some mentioned that these meanings were negative and compared them to carrying a cross and being closer to death. They also mentioned feeling guilty and depressed due to their infection. One participant stated that living in a body with HIV/AIDS prevented him from living a normal life. They described their bodies as frail entities affected by the large amounts of medications that they had to adhere. They felt limited in the activities they could undertake and in their sexual lives since they avoided this type of interaction with other people. When sexual interaction was available they felt the need to inform the potential partner of their serostatus due to the guilt that emanated from the possibility of infection. The need to take excessive care of their bodies was mentioned as a negative consequence of living with HIV/AIDS.

Yes, it's something you have (HIV). It's like a little spot on a white sheet. You take a white sheet and let a black spot fall on it. Even if you keep washing it, the spot stays there. MIDU

...I was a person concerned with how I dressed, had many friends, many girlfriends at work, many good things going for me and since I found out I had HIV, I don't know... It has unmotivated me tremendously. I have stopped loving myself. I think I am guilty... MIDU

It's negative you know... I can't see anything else. I can't see anything that can help me. I try and try but, nothing. HET

Torment, torment, torment. Is there anything good about it? Living in a body infected with HIV/AIDS? I don't think there is anything good because you know that you will die faster. HET

Well, before I was never as conscious of my body. I was always thin. I did not pay attention to how I looked. I felt comfortable. Now with HIV, since there were so many changes at one time... muscle mass or fat redistribution, sometimes I feel self-conscious about it. HOM

Look, when I did not know I was HIV positive I took more care of my body. I gave myself massages. Now, I just put on some cream but...I don't see my body as before. If I look at myself in the mirror I see it old, it's wasting. HET

Yes, my love life, the ladies. Because I am a man... and I like the ladies, with all due respect. But I can't wait (to tell them) until I'm there. Because I am, in other words, killing and harming that person. But then if I tell her the truth and she rejects me... how will I feel? There are some people than you tell them and they say "at least he was honest, let's give him a chance". But others don't. MIDU

Other participants attributed positive meanings to living in a body with HIV/AIDS. They mentioned the need to take care of their bodies with more emphasis as a positive outcome of HIV infection. This detailed care fostered their desire to live and improved their quality of life.

I don't know. I've never looked at it that way. Maybe I look at it more from the perspective of who I am, rather than the body I am. At this moment I can tell you... feeling infected with HIV is recognizing the human, the capacity, the desire to live, that I can be. I don't see it as a body and this separate entity, and look at it as a body. Sometimes I think that there are people that were born without an arm, may develop a problem with skin pigmentation, and I say they have a condition a little more obvious than mine. HOM

It means care. Care, because I have to take care of myself. HET

I find that now, from today's perspective, it was negative. Before I did not worry. Before I used drugs, stayed out late, ate things that now I see were not beneficial. Of course, when one is young one takes it all in without problems, but I see that I was doing incorrect things. It was negative that way. HOM

Yes, well, before... As you can see I am a little fat and before I did not worry about feeling well or looking good. I do now. Now I take more care of myself. Why? Because I have to fight against something I have; it is I who has to beat it. One of the positive things is having high self esteem. That is what helps me. My body, I am the one who has to deal with it, it's no one else. ...my high self esteem helps me to exercise, feel good, feel comfortable. Being able to say "I can do this, I can do that". Not feeling useless is a positive thing for me, and my health. Since its positive for my health, my self-esteem grows because I feel well. HET

The Perfect Body?

In light of the negative and positive meanings attributed to living in a body with HIV/AIDS, participants mentioned criteria for them to consider their bodies as perfect. Many reported that being seronegative would be the most important criterion. Nevertheless, other criteria surpassed HIV and included aesthetic qualities such as weight

loss and a reduction in breast size. The idea that their bodies were not normal was also documented in the interviews.

Well, ideally it would be not having HIV because I wouldn't have to take a bunch of medicines and obviously wouldn't have a lot of secondary effects. HOM

Not having HIV. Not having HIV anymore. I understand that my explanation regarding the body is that. Without HIV I don't have to work so hard, I am normal and for me normal is perfect. With my HIV I am not normal. I begin to become distorted in all ways. My face, body, everything. Obviously when your face and body start to distort, your mind starts to distort also because you are affected. Many patients have lost the will to live because of the rejection. The rejection is due to one's external appearance. I think nothing is being done about it. No funding is being assigned for things that doctors consider cosmetic. Which they aren't, because they affect your mind. People abandon themselves and lay down to die. HOM

No, I am very satisfied. I look at myself in the mirror and see myself as beautiful. I am eager to go to the gym, but it's because of this belly I have. I am not interested in losing weight in my hips or bust. The only thing that interests me is losing this belly and nothing else. HOM

In summary, the quotations gathered from the qualitative interviews evidence the body's important in the HIV/AIDS stigmatization process in two way: (1) as an identifier to others of HIV infection and as a trigger for stigmatization, and (2) as generating negative interpretations which promote self-stigmatization among PLWHA. In the following section we describe some of the implications of this study for further research on AIDS stigma.

Discussion

Our results evidence that the body serves as a vehicle for social as well as self-stigmatization. Participants vividly described the manner in which their bodies evidenced their HIV status to others, and how this fostered stigmatization and negatively influenced social interaction. This fact is particularly important for AIDS stigma research as it points to the need to incorporate the body's role in the stigmatization process. Participants' responses fit with Goffman's (1963) conceptual framework confirming that the body serves as a mechanism to initiate stigmatization upon identification of a mark which establishes differences. In this case, the bodily consequences of HIV/AIDS (marks, wasting, and lipodystrophy, among others) fostered stigmatization from people with whom participants interacted.

Some participants mentioned that their bodies did not evidence their serostatus, but were quick to admit that they actively engaged in "taking care" of themselves to achieve this. This is particularly interesting since it encompasses two underlying ideas: 1)

participants are aware that their bodies may show symptoms of HIV infection at any time and therefore must constantly subject themselves to regimes of self preservation (e.g., exercise, medications, and fine clothing, among others), and 2) participants view PLWHA with body marks as “others” who do not engage in such regimes, and therefore are in some part responsible for their body marks. This last theme highlights another dimension of stigmatization, this time directed at PLWHA from other PLWHA. These answers could also be interpreted as being mediated by social desirability. Participants may have avoided recognizing body marks in themselves fearing further stigmatization.

Body marks were a common theme throughout the interviews and participants highlighted how their existence negatively influenced social interaction. Participants informed that when such marks were visible, people avoided interacting with them. This fact also serves to highlight the body’s important role in the stigmatization process by others. Still, another important dimension of the body’s role in AIDS stigma is evidenced in the quotations regarding self-stigmatization.

Participants frequently spoke of the meanings they attached to their bodies once they started living with HIV/AIDS. Most of the descriptions addressed negative meanings, particularly the issue of abnormality. Participants mentioned that living with HIV made them feel like they were abnormal. They described their lives, bodies, and sexuality as being negatively influenced by HIV and therefore not being like other people: normal. Seeking “normality” is particularly troublesome since it fosters self-stigmatization among PLWHA. This is evidenced by the negative consequences mentioned from living in a body with HIV/AIDS which included feelings of guilt, no longer caring about their bodies, and the idea of having to “deal with” their bodies. Although engaging in self-presentation regimes was sometimes described as positive, most participants described negative consequences of living in a body with HIV.

Negative conceptualizations of the body with HIV/AIDS are only worsened by participants’ criteria for having a “perfect” body. The most common response was not having HIV/AIDS. This is particularly worrisome when participants associate having a “distorted” body with a “distorted” mind; the latter a consequence of the former. This association clearly evidences the body’s importance in the self-stigmatization process as it is described as a critical agent for mental health. Again, the issue of abnormality arises when participants feel that this goal is unattainable once they are infected with HIV.

Implications of this study for AIDS stigma research are multidimensional. If PLWHA develop negative notions regarding their bodies and the manner they understand others perceive it, the stigmatization process is facilitated, encouraged, and harder to confront. Nevertheless, these results should not be interpreted as unquestionable and unchangeable truths. Health professionals and researchers have to develop and implement an urgent agenda to address the stigmatization of HIV/AIDS and the body’s role in this process.

Upon completion of the study we have presented the findings to several groups of PLWHA, including participants, in visits to the CBOs that recruited them. Their reactions to the findings have strengthened our research since they agreed with our interpretations. Furthermore, they have recommended that we train health professionals on the subject of AIDS stigma. We have taken this recommendation and implemented it through an intervention we developed in light of the findings to reduce AIDS stigma among health professionals (Varas-Díaz, Serrano-García, & Toro-Alfonso, 2004).

In accordance with the results of the study we recommend the following:

1. Behavior specialists must develop and test interventions to address the effects of stigmatization on PLWHA, considering the important role that the body plays in the process. These efforts must include PLWHA's perspectives on the meanings they attribute to their bodies and their role in the stigmatization process.

2. Health professionals (e.g., physicians, nurses, and psychologists, among others) must be trained regarding the consequences of bodily changes in PLWHA. The idea that these changes have merely cosmetic consequences needs to be challenged in order to foster better services directed at this specific phenomenon.

3. Health professionals must increase their involvement in community efforts, such as activism and community work, aimed at changing policies in government and health insurance companies that hinder services for PLWHA to address the bodily consequences of infection (e.g., wasting, lipodystrophy). This is particularly important for secondary effects that are commonly labeled as cosmetic.

4. AIDS stigma researchers must address its consequences on the lives of PLWHA, particularly on its bodily dimensions. In order to achieve this we must surpass the overwhelming need to solely identify the psychological consequences of stigma (e.g., depression, low self-esteem), and start looking into the physical and structural dimensions that mediate those consequences such as the body, social oppression, and poverty, among others.

5. Research techniques must be implemented that address the qualitative aspects of personal interpretations of body changes, while also monitoring clinical adherence to treatment, viral load, and CD4 count. Mixed methods approaches may yield useful information that can be used in intervention development.

The challenges that lay ahead for professionals interested in AIDS stigma are many. The need to get involved in its study and to develop ways to address it is urgent. Still, the challenges that PLWHA face are even greater since they confront stigmatization on a daily basis. The need to incorporate different subjects into stigma research is evident. Let us embrace the possibilities generated by research on the meanings of the body with HIV/AIDS in order to improve strategies to challenge AIDS stigma.

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