THE EXPERIENCE OF STIGMA AND DISCRIMINATION IN MEN WHO HAVE SEX WITH MEN (MSM) LIVING WITH HIV IN SÃO PAULO, BRAZIL

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Abstract
Ever since it started, the AIDS epidemic has created a series of social representations that impact negatively on the daily life of MSM living with HIV, who feel doubly stigmatized. This association, made all the more potent by stigmas, is seen in acts of discrimination and physical and psychological violence. The general purpose of this study is to investigate the experience of stigma and discrimination in MSM living with HIV, while it specifically sets out to investigate the possible implications that HIV can have for HIV-positive individuals as regards their perception of the disease, themselves as infected persons, their social circle, their sexual behaviour and the situations of vulnerability that are involved. The final objective of the investigation is to analyze the different experiences of those infected before and after the antiretroviral therapy (ART). The study is based on the theory of Social Representations, and the analytical method used was the qualitative-quantitative, Discourse of the Collective Subject (DSC). The 33 participants, aged from 20 to 60 years old, were selected at a Centre for HIV/AIDS Treatment in São Bernardo do Campo, São Paulo, Brazil. The results pointed to high rates of internalized stigma, feelings of fear, rejection, a constant state of alertness and guilt. This perception was reflected in increased vulnerability by not using condoms, fear of being assaulted, social isolation and suffering. The study concludes that we need to investigate the social, affective and sexual contexts in which these individuals live, to rethink new forms of prevention and encouraging people who live with HIV (PLWHIV) to adhere to treatment.

Key-words: HIV/AIDS, Men who have sex with men (MSM), stigma and discrimination.

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Introduction

The perception of stigma and discrimination mentioned by PLWHIV is a problem that has been discussed as one of the great obstacles to be faced in the current phase of the epidemic. Since it was discovered, AIDS has been characterized by various social representations whose repercussions are still felt today. Due to the fact that the majority of the first recorded cases of the disease involved homosexuals – a fact endlessly exploited by the sensationalist media – AIDS came to be associated with sexuality, promiscuity and marginalized forms of behaviour. The immediate social repercussion manifested by the panic of collective hysteria, persecution and censorship of certain forms of behaviour, contributed to the growing process of stigmatization.

Following decades of military rule in Brazil, the early 1980’s saw the beginning of the process of redemocratization. In this context, the news about AIDS served as an argument for the authorities to advocate a return to arbitrary rule and moral control (Parker et al., 1991). This meant that the social conquests concerning freedom of sexual orientation won after considerable struggle on the part of social movements during that period were inverted and replaced by censorship, prejudice and discrimination. In the last three decades of living with the threat of AIDS, we have witnessed the great medical conquest that changed a death sentence into chronic disease. Nonetheless, this did not take place in the social sphere, where stigma and discrimination are still disseminated in the same perception as before, full of reprehension, judgment and blame cast at PLWHIV. Accordingly, what we observe is the force of a deeply stigmatizing social representation of the stigma, laden with content of a markedly moralistic, prejudiced and excluding nature (Kahhale et al., 2010).

The strong presence of stigma and discrimination is one of the main challenges to be faced in the struggle against the epidemic. Only by means of a “cultural revolution” (Paiva, 2000), sustained and supported by social solidarity (Parker, 2000), will it be possible to overcome these harmful aspects of the epidemic that blame and jeopardize PLWHIV in such a drastic manner and make them more vulnerable. **Prejudice, discrimination and stigma**, used in this study as categories of analysis, appear in the specialized literature on the matter. According to Bobbio (1992, p. 204), prejudice is an “opinion or set of opinions gathered passively and acritically by tradition, custom or by an authority whose determinations are accepted without argument”. Prejudice establish power relations, contesting ethical values (Sennett, 1999; Goffman, 2008); and act as a rationalized form of social control (Taussig, 1993). Discrimination, as defined by ONUSIDA (2005, p.09), “refers to any form of arbitrary distinction, exclusion or restrictions that affect a person, normally - but not only – due to an inherent or perceptible personal characteristic related to a given group – in the case of HIV/AIDS, when confirmed or suspected – whether such attitudes are justified or not”. Discrimination, present in the sexual, racial or religious field, consolidates social exclusion (Santos, 2011). As for stigma, this is a form of condemnation, segregation and penalization; a socially constructed ideology of disapproval, devalorization and separation (Goffman, 2008). When associated with HIV, this context potentializes a series of feelings that weaken, exclude and isolate PLWHIV (Kahhale et al., 2010). The concept of vulnerability, another variable analyzed in this study, represents a great step forward because of its broad, interdisciplinary way of evaluating the various susceptibilities of individuals and collectivities to HIV infection. This process, directed by different individual, social and programmatic applications, leads to an integrated understanding of intersectorial actions (Ayres, 2003).

The principal objective of this study was to investigate the experience of stigma and discrimination in MSM HIV+; and the specific objectives included investigating the possible implications that HIV can entail in MSM, in respect to perception of the disease, themselves as infected persons, their social network, their sexual behaviour and the contexts of vulnerability involved, as well as the differences in the experiences of those who became infected before and those who became infected after ART.
Method
The method chosen as a basis to allow investigating and analyzing the data was the Theory of Social Representations defined by Moscovici, (1981, p. 181) as "a set of concepts, propositions and explanations derived from daily life in the course of interpersonal communications", which enables us to investigate and analyze what is (re)produced by "common sense".

The Criteria for Inclusion were: 1) MSM; 2) over 18 years old; and 3) undergoing treatment at the CRT/STD/AIDS.

The analytical method in the interviews was the Discourse of the Collective Subject (DCS), designed to gather and describe social representations in the form of "collective discourses" that reveal how people perceive, reflect and attribute meanings and attitudes vis-à-vis events in which they participate. The method enables the subject to express one or more opinions on each issue. The DCS involves various operations in respect to the interviews held; these operations allow for individual statements that present similar meanings for the unique discourse, thereby representing a collective opinion (Lefevre et al., 2005; 2010).

The final result of the survey is that there are several DCS on the theme among the population researched. The data was processed using quali-quantitative software (www.spi-net.com.br).

Instruments: (1) Socio-demographic questionnaire (ABIPEME); (2) Interview: semi-directed with ten open questions related to the objectives, all of them quali-quantitative and including a fictional story with projective characteristics.

Procedure: Selecting the participants involved a meeting with the whole team of professionals from the institution responsible for the treatment of MSM HIV+, where all the details of the project were presented and discussed. It was agreed that the team would select and refer those selected – in accordance with the criterion for inclusion – for an interview at a pre-scheduled time between the researcher and the directors of the institution. Before each interview began, a Term of Free and Informed Consent (TFIC) authorized by the Ethics Committee of the Pontifical Catholic University at São Paulo (PUC-São Paulo) under Research Protocol number 223/2011 was explained and signed. The interviews were conducted individually, recorded and later transcribed, all with the prior authorization of those taking part in the survey.

Results and Discussion.
The 33 MSM HIV+ selected at the CRT/DST/AIDS in São Bernardo do Campo, São Paulo, Brazil, presented the following socio-demographic characteristics: (a) age bracket between 20 and 60, with 4 aged 20-30, 9 aged 31-40, 8 aged 41-50 and 12 aged 51-60; (b) ethnic group: 17 white, 14 mestizo and 2 black; (c) married status: 14 single, 3 divorced, 8 married and 8 with a common-law marriage; (d) level of education: 4 with level 1 of elementary school; 7 with level 2 of elementary school II; 13 with secondary school, and 8 with university; (e) sexual behaviour: 21 MSM and 12 MSMW (men who have sex with men and women); (f) history of infection: 24 individuals infected after 9 infected before ART.

After analysis of the interviews, results obtained have formed seven collective discourses:

1) The perception of the disease was addressed by the following question: What does living with HIV mean to you? One third of the interviewees demonstrated emotional strength to face the disease through adaptation, discipline and awareness of living with HIV, these being very important elements in the treatment: The essential thing to survive with HIV is discipline... I feel very well, healthy and productive. Conversely, the majority demonstrated feelings of fear, suffering and uncertainty as to the future: My life is over... I’m going to kill myself... It isn’t easy living with HIV virus... I can’t accept it, it’s all very complicated... a great deal of uncertainty as to the future, I’m afraid of the consequences. The HIV diagnosis is perceived as a triggering of different ways to face the situation, marked by suffering and enormous difficulties in living with the virus.
2) The perception of the social network was addressed by the two following questions, the first one of a quantitative nature: Whom have you told that you are HIV-positive? Friends 7, Family 16, Everyone 6, Companion 7. The total sum of 36 is justified by the possibility of revealing more than one member of the person’s social circle. Despite being mostly concentrated on the family, when this piece of information was analyzed qualitatively, it was discovered that the concept of “family” is very different from the conventional one, being comprised mainly by close friends who “could really be relied upon”, and by the companion. Our attention was caught by the fact that only 7 participants mentioned their companion. Revealing this datum may be important to guide future preventive actions, inasmuch as it discriminates the traditional family nucleus as being essential for support.

In pursuing the qualitative investigation of the question: How was that experience of revelation? Half of the interviewees declared a priori that this was a positive experience: I picked a few friends that I knew I could talk to calmly because they were aware of things. Most people accepted it, I think they internalized it all and then forgot it... The reaction was support, solidarity... I enjoy total - absolutely total - support from my sisters. Others had a negative, stigmatizing and discriminatory experience that led to reclusion and increasing isolation: I didn’t mention this to anyone because it’s all so prejudiced... I never had the courage to reveal the situation. People are so ignorant about this whole issue, they’re very prejudiced... My mother’s prejudice alone kills me, she doesn’t accept me... she’s very prejudiced. In all the situations reported in the survey, to a greater or lesser degree, we noticed difficulties in dealing with moral judgments, censorship and discrimination in the respective social networks.

Communicating the diagnosis is a moment of enormous suffering that brings into play feelings of self-condemnation and desolation. The perception of accusation, censoring, distancing and refusal of support from one’s social circle leaves one in a state of constant alert for the fear of being discovered, judged and made to feel inferior. In this process, low self-esteem, depression, helplessness, among other negative feelings, make one increasingly more isolated, impotent and without any resources with which to face and cope with the disease.

3) The perception of stigma and discrimination was addressed in the following question: Have you ever experienced or do you now experience any sort of prejudice or discrimination? The question was raised and perceived in different ways. Those who kept the diagnosis “secret” reacted to discrimination with persecutory and defensive feelings: If they find out tomorrow or later, I’m dead... Nobody forgives. They felt marginalized, excluded, hypervigilant and mobilized by devastating psychic suffering, especially the fear of having their homosexuality discovered: Are you queer? And then no-one will respect you anymore, you’ll never be a person again, people literally avoid you... It’s like being labelled.

In this way, the feelings of inferiority and exclusion because of heteronormativity potentialize vulnerability. These indicators point to the importance of paying close attention to the subjectivity of PLWHIV, and helping them to find strategies to deal with their psychic suffering.

4) The perception of sexual behaviour was addressed by the question: How do you think HIV+ homosexuals are seen? Homosexuality combined with HIV was perceived as humiliating, offensive and blameworthy. You’re looked on as “something”, a worm, burdened of punishment, a bit of “you deserved it”. Besides being queer, you’re a rotten queer. So the HIV homosexual is seen as a propagator of diseases, dirty, rotten, a freak, a race no-one wants to be close to, no-one likes, hardly anyone accepts and everyone accuses you. These data very well represent the depth of their anguish. This self-perception of exclusion, marginalization and guilt produces responsibilization for the infection, just as at the outset of the epidemic.
In this way, hegemonic and normative representations are perceived to potentialize anguish and suffering among MSM HIV+.

5) The perception of the infected individual about changes in their lives was addressed in the question: What has changed in your life since you were diagnosed with HIV? The diagnosis of HIV is perceived as a great mobilizer of changes. For some, a positive perception demonstrated an "alliance with life" that activated emotional resources such as introspection, strength, vitality and adaptation, all very important elements to face living with HIV: It's an ill wind that blows no good! Today I feel that I am a much better person than before... Today I have become a better person inside. So it's as if I had come to embrace a great challenge... Others see the change in negative terms, something stigmatizing and discriminatory that makes it difficult to relate to others because of the perception of abandonment, rejection and exclusion: I would say that today has lost all meaning. I try, I drag myself along to carry on... I don't know if I'll manage, I'm trying... My appearance has changed, I know I'm not the same and that I seem strange, just look at my face and arms. I'll never be the same as I was, I'm ashamed... My life isn't like what it was before, you know?... I feel rejected, I'm not normal anymore, you get it?... At times I wake up and would prefer to be dead, to die. No-one accepts you. It's a lousy life, man, not even the devil lived like this. It's unacceptable, it's hopeless. Both perceptions spring from intense feelings mobilized by the difficult and complex path that HSH HIV+ tread. These data are a warning of the importance of sheltering and paying attention to their subjectivity by stimulating reflection that can empower and help them face their situation.

6) The perception of contexts of vulnerability was addressed in the following question: What are the main risks a homosexual living with HIV runs? The data gathered are listed in chart 1 below:

<table>
<thead>
<tr>
<th>Core ideas</th>
<th>N</th>
<th>%</th>
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<tbody>
<tr>
<td>A- Difficulty in facing prejudice</td>
<td>21</td>
<td>63.63</td>
</tr>
<tr>
<td>B- Fear of other infections and infecting other people</td>
<td>17</td>
<td>51.51</td>
</tr>
<tr>
<td>C- Fear of having one’s homosexuality exposed</td>
<td>12</td>
<td>36.36</td>
</tr>
<tr>
<td>D- Fear of losing one’s job and not having social security</td>
<td>5</td>
<td>15.15</td>
</tr>
<tr>
<td>E- Fear of no longer having pleasure</td>
<td>3</td>
<td>9.09</td>
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Chart 1: Numbers refer to key ideas concerning the question.

This perception was demonstrated by difficulties in facing the situation and many fears, including retaliation, which produced hypervigilance and mistrust. If the police see us, we can be arrested... the danger is for them to find out and end up killing us... you can lose your job... the constant risk of being discriminated against in front of your friends. The fears of getting new infections and infecting others were seen to result from a persecutory instinct, efficacious information and awareness of self-care. The fear of having one’s sexuality exposed confirms the alarming statistics provided by Mott (2011), namely, that every 36 hours a homosexual is killed in Brazil with signs of cruelty. This is what makes them live with the insecurity of the disease and the fear of violence fueled by stigma and discrimination. These statements of suffering, guilt, feelings of inferiority, shame and fear of loss of civil rights denounce the deleterious effects of the perception of stigma and discrimination on the part of MSM HIV+.
7) **The perception of vulnerability due to not using condoms** – considered to be the principal tool in the fight against sexually transmissible diseases (STDs) and (re)infection by HIV – this question was addressed in this study using the following fictitious story:

... At a party, Carlos and João felt a deep attraction to one another. João offered Carlos a lift home and on the way invited him to go to his house. Arriving there, they drank and embraced one another and began to have sex. When Carlos noticed that João was going to penetrate him without a condom, he drew back. João said that he didn’t like to wear condoms and that to say such a thing at that moment was a sign of lack of trust. He told Carlos that they both good-looking and healthy and that he would never have sex with him if he thought that he was promiscuous. Carlos, feeling very unsure and yet hesitating to insist on the use of a condom and fearing that João would be “hurt”, gave in. They were at it for a long time, and then they drank more and more until João felt more at ease and let himself be penetrated by Carlos, saying that he was repaying Carlos for the proof of “trust” that he had shown. They surrendered mutually to that exciting situation...

After hearing this story, all the persons interviewed – 100% – affirmed that YES (just as in the story), not using a condom happens frequently: *I believe it happens with all those who today are infected with HIV... This, unfortunately, is very normal and that is why the number of contaminated people is still growing: because of all this ‘proof of trust’... I think that 80% of people don’t bother to use condoms. It’s that old story of: "Look at me. You don’t trust me ".... But everybody does that, nobody gives a damn, fuck the others. When your head is full of rum, you don’t remember anything... And it’s fucking awful, man, 'cause after you catch this worm, no woman comes near you, so all that devil energy keeps piling up inside and then when you least expect it you’re trying to get some relief, you know... I think that people is (sic) driven so much by sheer horniness, by desire just because the other guy is good-looking, because he has a terrific body... So I think that this happens every 10 minutes, all over the world. Definitely!*

They were unanimous in admitting the probability of **not using condoms**, which explains the high degree of vulnerability of this risk behavior. In the qualitative investigation of this datum, where the participants were instigated to make a personal reflection that might justify such behavior, the indices were justified by **impulsiveness, pleasure in subservience and extreme excitement under the effect of alcohol and chemical substances**. These data underscore the need to make a profound investigation into this type of behavior in future research.

**The perception of the ART effects in the experiences of the two groups**, those infected before and those after ART, was intertwined with prejudice, discrimination and isolation. The answers were similar, showing the internalized feelings of prejudice and discrimination in both groups. This contradicts the suspicion that with medication, PLWHIV would be less vulnerable to self-discrimination and feelings of inferiority. Isolation proved to be the major consequence of the diagnosis in both groups, regardless of ART. If prior to ART the diagnosis represented eminent physical death, this survey showed that the worst fear today is of social death.

The **limitation factor** is due to the fact that the in-depth interviews restricted the number of possible individuals in this study. Adding interviewed individuals in different cultures and locations could provide more information to enable us to make generalizations.
Conclusion

The internalized stigma demonstrated by the participants revealed the devastating effects on the quality of emotional and social life, as observed in the reports of situations of humiliation, degradation and disrespect. Social denial of the stigma and discrimination led them to isolation by making them more vulnerable to the non-use of condoms and consequently re-infection as a result of low self-esteem and self-depreciation. In this sense we see that the body and sex are the vehicles that best express the profound emotional imbalance in the behavior of these individuals.

In conclusion, this investigation points to the need for campaigns of a non-moralistic focus, equipped with a deep knowledge of the social, emotional and sexual contexts of MSM HIV+, lending due value and respect to the individual whatever his/her sexual behaviour may be. This understanding, based on respect for difference, of human rights, citizens’ rights and sexual rights, together with frequent interdisciplinary dialogues, will help individuals to prepare themselves to cope with HIV infection.

References


