

Pedro B. Garrido<sup>I</sup>

Vera Paiva<sup>I</sup>

Vanda L. V. do Nascimento<sup>II</sup>

João B. Sousa<sup>III</sup>

Naila J. S. Santos<sup>III</sup>

# AIDS, stigma and unemployment: implications for health services

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## ABSTRACT

**OBJECTIVE:** To analyze the effect of the stigmatization and discrimination process in the work environment on the routine healthcare and well-being of men living with HIV/AIDS.

**METHODS:** Qualitative study with 17 men living with HIV, conducted in 2002. Testimonies given in a group to discuss the difficulties concerning discrimination in the work environment were studied, by means of discursive practice analysis. The group, originating from a specialized center for HIV/AIDS treatment in the city of São Paulo, represented a segment of previous research.

**RESULTS:** The discussion among participants pointed out the fact that antiretroviral treatment requires frequent visits to medical assistance services, resulting in absences and delays at work. To show medical certificates to justify absences at work, even without indicating AIDS, can lead to dismissal. Unemployed, many are barred during medical examinations and have their right to confidentiality violated. As a last resource, the request for retirement results in a humiliating or discriminatory scene during the medical inspection.

**CONCLUSIONS:** Assistance planned with the patients' participation enables the broadening of psychosocial attention and the consideration of the needs of both employed and unemployed patients, acknowledging that the stigma limits care, affecting mental health and the evolution of infection. To reduce the effect of stigma and discrimination is something that requires intersectoral political articulation and will contribute to reach goals that are globally recognized as fundamental to control the epidemic.

**KEY WORDS:** Men. Acquired immunodeficiency syndrome, psychology. Workers. Job satisfaction. Unemployment. Prejudice. Psychosocial deprivation. Occupational health.

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## INTRODUCTION

Stigma is a common situation involving infectious or mental illnesses, with implications recognized by several areas of public health.<sup>5,8,16</sup> In the case of AIDS, a variety of metaphors has intensified and legitimized the stigmatization process of both the "victims" and those "blamed for" spreading the pandemic all over the world.<sup>2,6,10</sup> HIV/AIDS are associated with imminent death, immoral behavior that deserves punishment, and the necessary war to stop the spread of the virus.<sup>6,12</sup> The stereotypes were the basis for numerous stigmatizing social and programmatic responses and have contributed to causing people not to recognize the situations that expose them to infection so that they are not identified

<sup>I</sup> Núcleo de Estudos para a Prevenção da AIDS. Instituto de Psicologia. Universidade de São Paulo. São Paulo, SP, Brasil

<sup>II</sup> Centro Universitário Capital. São Paulo, SP, Brasil

<sup>III</sup> Centro de Referência e Treinamento DST/AIDS-SP. Secretaria da Saúde do Estado de São Paulo. São Paulo, SP, Brasil

### Correspondence:

Vera Paiva  
Instituto de Psicologia da Universidade São Paulo  
Av. Prof. Mello Moraes, 1721  
05508-030 São Paulo, SP, Brasil  
E-mail: veroca@usp.br

with shameful, derogatory labels.<sup>6,10,\*</sup> To reduce the impact of stigma and discrimination related to AIDS is one of the transversal objectives of all the sectors dedicated to the epidemic control and enhancement of care given to those afflicted, the transversal objective of the HIV/AIDS commitment made by the United Nations General Assembly – UNGASS.<sup>7,11</sup>

Goffman<sup>4</sup> defined stigma as a significant discredit attributed to a person with an undesirable difference, and indicated that the stigma is a powerful sign of social control used to marginalize and dehumanize individuals who show certain undervalued traits. People who have undervalued traits may be “discredited” instantly, when these are visible in the daily life; or “discreditable”, when the traits are not immediately visible, but can be revealed or discovered.

More recently, Jacoby<sup>5</sup> identified two dimensions of the stigma experience, while studying people with epilepsy. The “felt stigma” makes people limit their routine unnecessarily, seeking isolation, for instance, as they feel afraid of discrimination. The “enacted stigma” refers to the actual experience of discrimination, when the exclusion due to stigma has already taken place, resulting in violation of rights and social ostracism. In the case of AIDS, Parker & Aggleton<sup>12</sup> discussed how disparaging, discrediting attributes can add to the process of stigmatization of people living with AIDS, attributes that already disqualified them as bearers of rights before the infection – such as being a sex worker, black, homosexual or unemployed. The stigma and discrimination associated with AIDS, as a result, frequently intensifies the social order that maintains the differences and pre-existing social inequalities such as the ones caused by sexism and racism.

One may wonder how people living with HIV deal with the stigma and discrimination associated with AIDS, and how healthcare services can support them to deal with discrimination and prevent stigmatization from being an obstacle to their well-being and access to healthcare. Thus, the objective of the present study was to describe how the effects of the stigmatization and discrimination process in the work environment affect the well-being and healthcare of men living with HIV/AIDS.

## METHODOLOGICAL PROCEDURES

The present study constituted the second stage of qualitative/quantitative research carried out with the objective of describing how men, who live with AIDS and have sexual intercourse with women, perceive their healthcare and care for themselves, especially as

regards sexual and reproductive health. In the first stage of the research<sup>3,10</sup> a consecutive sample of patients from two specialized centers for HIV/AIDS in the city of São Paulo was invited to answer a questionnaire-based interview with open and closed questions, according to the order of arrival at the services for consultation with an infectologist.

The criteria for inclusion were: to be male, to show good conditions of physical and mental health, to be 18 or older and to be sexually active with women. In one of the centers, all the interviewees were invited to participate in the subsequent second stage, according to the same criteria. The participants in the first meeting raised issues for discussion in the four follow-up group sessions whose objective was, at the same time, to support them as agents of their self-care. The themes the participants pointed out were: the wish for and the possibility to have children; work and difficulties faced to get a job and keep it; difficulties to begin and keep romantic relationships and safe sex; prejudice. The group sessions went on for two hours, in the format of a focus group, assisted by two researchers, and coordinated by a psychologist, recorded and transcribed.

The analysis of discourse practice<sup>13</sup> was chosen as it aims at understanding the language in use as a social practice. This study was approved by the ethics committees of the institutions involved. The names of participants are fictitious.

## ANALYSIS OF RESULTS

The 17 participants in the follow-up stage expressed the profile diversity of all the 125 individuals interviewed in the first stage of this study in that specialized center: hetero or bisexual, drug users or not, men with or without children, employed or unemployed, retired or with benefits (sick pay), in different age groups. The participants spoke of difficulties to get a job and keep it, and the theme of discrimination appeared as a discussion articulator. Discrimination was understood as a major obstacle to the well-being of participants, something that affects their male identity, with implications for the health that are little considered in the planning of assistance.

The Table shows the characterization of men according to their work situation, as they reported it. A total of four men out of the 17 participants in the group related that they were dismissed, and five others resigned because they were seropositive. Some of them are in more than one category, which points to the vulnerability of this group to enacted stigma (discrimination), resulting from the stigmatization process.

\* Nascimento VLV. Social practices in discriminatory situations in the AIDS scenario: on rights, demands and recommendations [Doctorate thesis] São Paulo: Programa de Estudos Pós-Graduados em Psicologia Social (Program of Postgraduate Studies on Social Psychology) at the Pontifícia Universidade Católica in São Paulo; 2007.

**Table.** Work situation of the 17 male participants in the support group, in an outpatient ward for STD/AIDS. City of São Paulo, 2002.

Participants	Retirement/Sick benefit	Current work situation	Being seropositive, he was: dismissed/resigned
Artur	Retirement for invalid status	Street vendor	-
Léo	Sick benefit being processed	Unemployed	-
Paulo	Retirement for invalid status	Radio broadcaster	Dismissed
Jorge	Not mentioned	Not mentioned	Not mentioned
José	Retirement for invalid status	-	-
Felipe	Sick benefit	-	Resigned
Matias	Retirement for invalid status	-	-
Luis	Retirement for invalid status	-	Resigned
Manoel	Retirement for invalid status	Salesman	Dismissed
Djé	Retirement for invalid status	Unemployed	Dismissed
Beto	Retirement for invalid status	-	Resigned
Marco	Sick benefit being processed	Unemployed	Resigned
Daniel	Retirement for invalid status	Computer technician	Resigned
Nelson	-	Unemployed	Dismissed
Souza	-	Salesman	-
Lima	Retirement for old age	-	-
Inácio	Sick benefit	-	Resigned

The participants described how the care for health inherent in the seropositive condition causes absences or delays at work. To show medical certificates, even without indicating AIDS, marks the beginning of a process of visibility concerning the condition of seropositive and one's stigmatization, affecting one's situation as a "normal" employee, a recurrent word in group conversations. "Normal" was what all participants would like to be in the company they worked for. Artur described the difference between the seropositive employee and the normal employee:

*"I think the worst thing (...) for those who want to work like us is that you will have to be absent from work many more times than a normal employee. That's what I think ends up causing professional obstacles. You land a job, then, one day you get late because the CD4 dropped [immunity test], another day you leave early (...)"*

As soon as a "discreditable" aspect becomes visible, the stigmatized one risks losing rights – the right to healthcare or the right to work. At this moment of the process, in the scenes described, the boss looked suspicious, as suggested by the participants:

*"I used to work for a security agency and I would often have a fever at night. Then, the manager began to grow suspicious. One day, he asked me why I would have so many fevers at night. I said, 'I don't know.' He was already a bit suspicious. That was when I resigned, I left right after that."* (Luis)

*"At the last company I worked for, I stayed there for 12 years. As I had a consultation here once a month, the time came when my manager started questioning me why I had so many medical certificates. That's because he was suspicious (...) Why did he begin to pick on my bringing certificates, but nobody else's?"* (Paulo)

From the moment there is mistrust, one goes from the invisible to the visible (from the discreditable to the condition of discredited),<sup>4,5</sup> to the stigmatization and discrimination (to unemployment, for instance). The need to keep information invisible leaves clues that cause mistrust. To guarantee the right to privacy and the confidentiality regarding the seropositivity condition, the person living with HIV must develop their social interaction skills.

Paulo felt he had no means to prove he was dismissed due to discrimination. He tried to file a law suit against the company that dismissed him and realized he would need witnesses.

*"I think discrimination is something that, most times, is not explicit. You know you're being discriminated, but the guy doesn't say it, 'you're being dismissed because of this.' And it's a very delicate issue. I know this happened, why? Because I didn't have a promotion, my scholarship was close, it was turned down (...) Even the way he behaved towards me was different. I said to myself, 'How am I gonna prove this?' (...) I'd need two witnesses, but as I didn't come out, I had no witnesses"*

(...) You know, it's very hard to prove discrimination. Then, sometimes the company wins. They dismiss you and it's their word against yours (...) If you didn't tell anybody and the company doesn't know (...) there's no way you can get a witness." (Paulo)

When you are forced to "cover up", as defined by Goffman,<sup>4</sup> there can be no guarantee of witnesses.\*\*\* At the same time, the process of stigmatization composes the synergy of stigmas, as described by Parker & Aggleton.<sup>12</sup> Luis is black and he commented subsequently, "Discrimination is like racial prejudice: it exists, but it's all hidden." Artur related the job dismissal was also due to the ex-convict stigma.

The decision to tell or not to tell is experienced while the fear of discrimination takes shape, as clarified by Manoel:

"In 89 I found out about this disease, you know. Then, I went on without saying a word, I didn't want to tell my co-workers, I was afraid of being discriminated. (...) and my boss began to complain about me being absent often."

The alternatives in these situations would be to leave the job, to retire or to seek another job. In the following dialogue the right to work was mentioned:

Manoel: "You're filling out a form, then, you read, 'Do you have any serious health problems?' Are you gonna lie?"

Paulo: "No. If you wanna work, you write 'I do'."

Manoel: "Then, you know what's gonna happen."

Paulo: "But does this take away your right to work? You know, not everyone who's in an invalid condition is necessarily invalid."

Léo took part in a selection process and was turned down after the medical examination. He suspects that the right to privacy and confidentiality about his condition were not respected, according to the norms of the Ministry of Health.\*\* Later on, he abandoned the selection process when he realized he would be tested, agreeing with Paulo, who said he did not want to "go through this humiliation"

On the Table it can be noted that five participants declared they were working at the time of the interview. Daniel was self-employed and had been unemployed for two years after finding out about the diagnosis. Then, he slowly came back. Artur and Manoel were retired and sought a way out of their "invalid" condition in the informal work market.

"I'm retired. I am and I'm not, I have a small stand there, but, like, I can't stay there all the time. 'cause I do other things, I gotta take care of my health, I got doctors, I got..." (Artur)

"(...) I work as a salesman (...) The invalid pension plan does not allow us to work by law, you know, registered. So, I'm self-employed, I got no register, I got nothing..." (Manoel)

Ten men out of the 17 participants were retired (nine as invalid) and three with sick benefit. The invalid retirement or sick benefit is a conflicting way out and adds to the synergy of stigmas an especially delicate dimension for the self-esteem, because the male social identity values working out of home and providing for the family. Retiring may be the last resource and a "certificate of exclusion" as can be seen in the following dialogue:

Beto: "If the inspector doesn't give you your retirement, time passes by, he comes back to work and the company won't take him."

Artur: "The person (...) keeps looking for a job and finds nothing. Then, (...) I'm gonna try to retire. But the red tape to get to retirement is huge. I got my pension. Thank God, I had a lot of registered time. Still, I had to go through a lot of inspecting and a bunch of other things to get my pension."

Marco: "I'm trying to get my pension."

Felipe: "There's something else... to get into the INSS [National Institute of Social Security], we got to lie, 'cause if you show a good appearance and look neat there, you'll never make it..."

Artur: "I even fainted before the doctor, I fell down (...) I pretended to feel sick and all."

Souza: I began to live with people who participate here. (...) in the past, I would only talk with people who were in a better condition, I'd like to know what they ate, what they did. I learned a lot (...) and kept working. Then, they laid me off. Why didn't I notify the company? Now, I regret bitterly. 'cause I thought, it's a two-edged sword, I mean, if I go for the sick benefit, at my age, this will be my certificate of exclusion from the work market.

Nelson: "This rocks one's life. 'cause, like, I got a lot to do in my life yet... I want to look for work, I want something. The only way out is to retire, because (...)

\* Abbade ACS. Questões do direito do trabalho e do direito previdenciário no contexto da AIDS. In: Ministério da Saúde. Coordenação Nacional de DST e Aids. O outro como um semelhante: direitos humanos e AIDS. Brasília; Secretaria de Políticas de Saúde. Coordenação Nacional de DST e Aids; 2002. p. 93-108.

\*\* Ministério da Saúde. Secretaria de Políticas de Saúde. Coordenação Nacional de DST e Aids. Diretrizes dos Centros de Testagem e Aconselhamento (CTA): Manual. Brasília (DF); 1999.

*If someone discriminated me 'cause I'm seropositive, so the only way out is to retire?'*"

The opportunity to share experiences with other patients can help them not do identify themselves as invalids or to react to stigmatization processes that result in discrimination.<sup>2,9,15</sup> Throughout the group meetings, however, bisexual and heterosexual male participants reported feeling uncomfortable in support groups from non-governmental services and organizations, often frequented by gay movement activists with whom they do not always identify or would like to be identified.<sup>15</sup>

*"If you said you were seropositive, they give you this look like you are a lost case, a car that crashed and turned into a wreck, get it?... You go to a job interview (...) 'Hum, have you got something?' 'Well, I'm a diabetic.' You may even be tolerated. Now, if you say you're seropositive..., you know? 'Cause this makes people wonder: he's either homosexual or promiscuous, he fooled around with everyone in the city, you know? It's a problem... That's why I was in doubt: do I tell or not? 'Cause you end up feeling impotent. 'Cause if you reveal your serology, people already exclude you, they judge you 'Aw, poor guy! Look, it's a chronic and degenerative disease, there's no cure, he's gonna die tomorrow. He's gonna kick the bucket soon'." (Beto)*

The interviewees felt humiliated with the national system of social security, or humiliated themselves by playing up their fragility, following the "moral career" shared by several stigmatized groups,<sup>5</sup> suffering the psychosocial impact of "choosing" the "invalid" pension plan, lengthily discussed by the group. Some of them had periods of sickness that prevented them from working; others decided to "manipulate the stigma" or use "their disadvantage as a basis to reorganize their lives. However, in order to do so they must resign themselves to living in an incomplete world", as described by Goffman (1980, page 30).<sup>4</sup>

The attribution of incapacity associated with the invalid condition was not noticed as adequate.

*"Not because of the fact I'm seropositive (...) If I can work, if I've got the strength, if I've got the enthusiasm and can be productive, why not? If I'm retired like this, I can't contribute... This invalid thing is actually something for those who aren't really willing to do something. Then, I think this really rocks your life. If I'm capable, if I can (...)" (Nelson)*

*The doctor goes, 'According to such-and-such law, you've been granted your invalid pension'. That was quite a shock. You know, not everyone who is in an invalid condition is necessarily invalid. When I received my pension, I wasn't expecting to be retired due to 'invalid status'. I thought, 'I'm no invalid!' It's as if they said 'Listen, you're blind!' and I said, 'No, I can*

*see just fine!' I think what defines this invalid thing is something he mentioned two times here: you feel excluded, wronged, you know, unproductive. (...) Let's imagine we here are not seropositive and then we see the word 'physically handicapped' (...) The work market, now, offers an opportunity to this group [physically handicapped]. Am I excluded or included in this group of physically handicapped? (...) In fact, we're excluded, but we're not even included as physically handicapped, we're nowhere." (Paulo)*

*"(...) Because I don't feel crippled in any of my legs or arms. (...) Then, I find this kind of thinking strange, you know. Then, I feel like a victim of fate, because I'm considered invalid, but the kind of invalid who's as dexterous as a normal person." (Manoel)*

*"They should've made a specific law for HIV, not physically challenged or immunologically challenged. Something specific." (Daniel)*

However, not all the men who participated in the analyzed group were discriminated at work. Beto described how the stigma associated with AIDS affected daily routine, but he was supported by the company he worked for and did not lose the rights to work and healthcare:

*"In my case, it was the opposite of what people here are telling. My company gave me complete freedom to keep working. When I found out I was seropositive, I became deeply depressed and felt incapable of giving myself the opportunity to work in the area of Human Resources. The company said, 'You can come anytime you wish, leave anytime you wish, we're giving you carte blanche'."*

Beto's testimony shows that the participants in the present study did not receive a proper reception due to lack of preparation from the companies they worked for. With more relevance in the institutional domain, Brown et al<sup>3</sup> pointed out four types of intervention with an impact on the reduction of HIV/AIDS stigma: 1) use of educational material to lower rejection towards seropositives and boost community reception; 2) role-play to build up abilities to cope with fear and anxiety in group activities; 3) individual and group counseling to support non-stigmatizing behavior; 4) promotion of interaction with people who live with HIV. Work initiatives in public and private companies based on this approach or comparable to the ones that have been initiated by the *Programa Nacional de DST/Aids*<sup>12</sup> (National Program on STD/AIDS) should be promoted. Terto Jr<sup>15</sup> warns about the importance of expanding governmental and company policies that provide people living with HIV and their family with proper healthcare without their being discriminated. He points out that the employer can profit by promoting a healthy work environment, strengthening the positive image of the company, avoid-

ing law suits, and participating in the global effort for AIDS prevention, thus fulfilling an important role of social responsibility in the effort to reduce stigmatization towards people living with HIV.

Studies on people living with HIV/AIDS in Brazil<sup>1,9,10,15,\*,\*\*</sup> describe how the psychosocial impact of stigma in other interactions (with family, friends, neighbors and sex partners) leads to concealment, isolation and depression. Afraid of mistreatment and rejection, these people assess in each intersubjective context the possibility of being discriminated or not. On the other hand, in studies on women living with HIV<sup>9,10</sup> family dynamics and children appear to organize their concerns about stigmatization and discrimination more strongly than working out of home. In the case of men, the “invalid” issue gave strong sense to the humiliation and psychological pain resulting from stigmatization.

## FINAL CONSIDERATIONS

This study confirmed the importance of discrimination towards people living with HIV in the work place, described in the experiences of a group of men who are patients in a reference center for STD/AIDS, pointing to important implications for the public services that deal with those who have become ill.

The process of stigmatization can begin with the needs concerning antiretroviral treatment, which requires many consultations, absences and delays at work. Currently, such needs are more common than in the first decade of the epidemic, when becoming ill quickly resulted in death. These situations force people to reveal their diagnosis and lead to the stigmatization associated with AIDS, followed by discrimination. Many did not stand the pressure (or “humiliation”) and resigned, others were dismissed. Throughout the debate of the participants, it was noted that the confidentiality over their condition, a guaranteed right of the person living with HIV/AIDS, can be violated in the admission health exam, going against the norms of the Ministry of Health and State of São Paulo Law.<sup>\*\*\*</sup> The invalid pension plan can be a necessary restriction, a way out of the stigma of being unemployed, which adds the discredited invalid status to the attributes associated with AIDS, with an important emotional impact.

The qualitative analysis of the group process described some of the experiences about living with HIV. New

studies that estimate the prevalence of factors associated with these types of experiences are recommended.

The most immediate challenge is to promote effective interventions, initiated in the healthcare system, to decrease the effect of stigma and discrimination, admittedly frequent in the work environment. The reorganization of consultation and exam booking so as not to harm workers would be a specific contribution to healthcare services. However, the results from the present study stress the need for intersectoral answers, that is to say, answers that can reach other sectors, such as the national system of social security, or organize interventions in the field of cultural deconstruction of the stigma.

The individual capacity to resist the process of stigmatization and discrimination can be stimulated through the participation of patients in support and sharing groups. Planning the assistance with the participation of each patient would enable to identify how services can contribute to reduce the effect of discrimination in specific details of one’s routine, enhancing the quality of psychosocial attention.

To reduce the impact of stigmatization depends on actions in the legal sphere. Abbade<sup>\*\*\*\*</sup> relates situations involving arbitrary dismissal of employees suspected of having or actually being HIV-positive, (illegal) requirement of anti-HIV tests during admission or periodically, which have been restricted by legal actions. Negotiations between both parties have guaranteed reintegration of workers and compensation. Thus, it is essential to expand articulated actions with the media, justice and labor departments, and entities that protect the rights of workers and/or people living with HIV, aiming at discussing norms that take into consideration specific details of the limitations associated with HIV that result not only from the infection, but also from the process of stigmatization.

Stigmatization is a social process that plays a key role in the expansion of inequality and legitimizes the violation of human rights of people living with HIV, with repercussions for their well-being and integrity. Both the services of specialized attention for AIDS and the medical inspection for retirement must recognize the impact of stigma on the progression of infection (when hindering healthcare) or on mental health, especially when creating unnecessary situations of humiliation and discrimination, as in the case of unemployment.

\* Nascimento VLV. To tell or not to tell: people with HIV/AIDS revealing their diagnosis [Master’s dissertation]. São Paulo: Pontifícia Universidade Católica in São Paulo; 2002.

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\*\*\* Ministério da Saúde. Coordenação Nacional de DST e Aids. Legislação Brasileira sobre DST e Aids. (Ministry of Health. STD and AIDS Coordination Office. Brazilian Legislation on STD and AIDS) [Accessed on 5/28/2007] Available at: <http://www.aids.gov.br/data/Pages/LUMIS66512B3AITEMID9FA5F81FB9AF4ECF86453BF1E04D6B4BPTBRIE.htm>

\*\*\*\* Abbade ACS. Questões do direito do trabalho e do direito previdenciário no contexto da AIDS. In: Ministério da Saúde. Coordenação Nacional de DST e Aids. O outro como um semelhante: direitos humanos e AIDS. Brasília; Secretaria de Políticas de Saúde. Coordenação Nacional de DST e Aids; 2002. p. 93-108.

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