

## Social Representations of AIDS and their Quotidian Interfaces for People Living with HIV

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This qualitative descriptive study, guided by the Social Representations Theory, aimed to describe the content of the social representations regarding the Acquired Immunodeficiency Syndrome (AIDS) for seropositive individuals in outpatient monitoring of the public health network and to analyze the interface of the social representations of AIDS with the quotidian of the individuals living with human immunodeficiency virus (HIV), especially in the adherence to treatment process. Interviews were conducted with 30 seropositive individuals and the manual content analysis technique was used. From the analysis, six categories emerged that re-translated the quotidian of seropositive people permeated by the stigma, prejudice, struggle for life and the need for the continuous use of antiretrovirals. AIDS was assimilated to chronic diseases such as diabetes, showing a trend of transformation of the social representation of AIDS, substituting the idea of death, with life. It is concluded that people living with HIV are more optimistic due to effective treatments for the control of the disease.

Descriptors: Social Representations; HIV; Acquired Immunodeficiency Syndrome; Chronic Disease.

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## Representações sociais da AIDS para pessoas que vivem com HIV e suas interfaces cotidianas

Trata-se de estudo qualitativo descritivo, norteado pela teoria das representações sociais. Objetivou-se descrever o conteúdo das representações sociais acerca da síndrome de imunodeficiência adquirida (AIDS) para os usuários soropositivos, em acompanhamento ambulatorial da rede pública de saúde, e analisar a interface das representações sociais da AIDS com o cotidiano dos indivíduos que vivem com o vírus da imunodeficiência humana (HIV), especialmente no processo de adesão ao tratamento. Realizaram-se entrevistas com 30 indivíduos soropositivos. Utilizou-se a técnica de análise de conteúdo manual. Da análise, emergiram seis categorias que retraduziram o cotidiano de soropositivos, permeados pelo estigma, preconceito, luta pela vida e a necessidade do uso contínuo de antirretrovirais. A AIDS foi assimilada a doenças crônicas como diabetes, evidenciando tendência para transformação da representação social da AIDS, substituindo a ideia de morte, por vida. Conclui-se que as pessoas que convivem com HIV estão mais otimistas devido aos tratamentos eficazes no controle da doença.

Descritores: Representações sociais; HIV; Síndrome de Imunodeficiência Adquirida; Doença Crônica.

## Representaciones sociales del SIDA para personas que viven con HIV y sus interfaces cotidianas

Se trata de un estudio cualitativo descriptivo orientado por la Teoría de las Representaciones Sociales, que objetivó describir el contenido de las representaciones sociales acerca de la Síndrome de Inmunodeficiencia Adquirida (SIDA) para los usuarios seropositivos en acompañamiento de ambulatorio en la red pública de salud y analizar la interconexión de las representaciones sociales del Sida con lo cotidiano de los individuos que viven con el virus de la inmunodeficiencia humana (HIV), especialmente al proceso de adhesión al tratamiento. Se realizaron entrevistas con 30 individuos seropositivos. Se utilizó la técnica de análisis de contenido manual. Del análisis, emergieron seis categorías que tradujeron lo cotidiano de seropositivos impregnados por el estigma, prejuicio, lucha por la vida y la necesidad del uso continuo de antirretrovirales. El Sida fue comparado a enfermedades crónicas como la diabetes, evidenciando una tendencia de transformación de la representación social del Sida, substituyendo la idea de muerte, por la de vida. Se concluye que las personas que conviven con HIV están más optimistas debido a los tratamientos eficaces en el control de la enfermedad.

Descriptorios: Representaciones Sociales, VIH; Síndrome de Inmunodeficiencia Adquirida; Enfermedad Crónica.

## Introduction

AIDS represents one of the serious public health problems, characterized as a global epidemic with rapid dissemination and escalation. In this context, AIDS demands an urgent response and the need for economic, political, social and psychological resources that face a problem of such magnitude. At the beginning of the epidemic, it was considered, in the reified knowledge, a

disease that affects a restricted group, the so-called "risk group", which was constituted partly by homosexuals, hemophiliacs, Haitians, and heroin users, as well as sex workers. The use of this expression would mark the historical, cultural, imaginary and social construction of AIDS<sup>(1-2)</sup>. Subsequently, the epidemic was also associated with "risk behavior". This model was heavily criticized

for blaming the individual for having failed in prevention and/or protection efforts. This concept was substituted by that of vulnerability, since the chance of exposure of people to the human immunodeficiency virus (HIV), and the resulting illness, is not due to a set of individual, collective and contextual aspects<sup>(3)</sup>.

Considering the profound inequalities of the Brazilian society and the spread of HIV infection in the country, AIDS is revealed as an epidemic of multiple dimensions that is, over time, undergoing significant transformations in its epidemiological profile, and is today marked by its incidence in the female, heterosexual, rural, aging, lower educated, and poor populations<sup>(1-2)</sup>. However, in nearly three decades of the epidemic, progress is evident concerning the treatment of this disease because, with the advent of the antiretrovirals, there has been a significant improvement in the quality of life of people living with HIV. For this reason, AIDS now presents the characteristics of a chronic disease<sup>(4)</sup>.

In reflecting on its dissemination, the transformations of this epidemic in its historical context must be considered, especially in relation to the forms of transmission, the trends of disease vulnerability, and also the meanings constructed to face this reality. This study is justified by seeking to comprehend the representational universe and consensus of the HIV/AIDS seropositive users in outpatient monitoring. Giving voice to these subjects, who motivate and receive specific health actions, is a means which permits learning about their anxieties, fears, images, difficulties, attitudes, barriers and feelings constructed in the face of a diagnosis that constitutes a social phenomenon that has undergone transformations over time. Knowing the representations of the syndrome and its influence on the various facets of experiences constructed in the quotidian of these subjects will contribute to improving the quality of life of those living with HIV, through more adequate and satisfactory health actions.

In this sense, the following aims were adopted: to describe the content of the social representations regarding AIDS for seropositive individuals in outpatient monitoring of the public health network and to analyze the interface of the social representations of AIDS with the quotidian of the individuals living with HIV, in relation to adherence to treatment

## Methodology

This was an exploratory descriptive study, with a qualitative approach, based on the Social Representations

Theory (SRT). This theory can be defined as socially produced and shared knowledge with a practical aim that contributes to the construction of a common reality of a social group. It may be equally designated as common-sense or naivety, i.e. natural<sup>(5)</sup>.

The study was conducted in a Municipal Public Hospital in the city of Rio de Janeiro, a specialized reference center for HIV seropositive clients. The research was developed in light of the ethical provisions presented as development standards and guidelines for research with human subjects contained in Resolution 196 of October 10, 1996, of the National Health Council (NHC)<sup>(6)</sup>, having been approved by the Ethics Committee of the Municipal Health Secretariat of the municipality of Rio de Janeiro through Protocol No. 200/08.

A total of 30 users of the institution, 14 male and 16 female, participated in the study, all of them over 18 years of age, in outpatient treatment for at least 6 months from diagnosis and using antiretrovirals. The users were invited to participate in the survey at random, while in the waiting room awaiting a routine medical consultation. After acceptance, the Terms of Free Prior Informed Consent was explained and signed as a precondition for the performance of the interview. The number of subjects was established according to the consensus among researchers in the field of social representations as the minimum needed to recover a cognitive and social construction regarding an object.

For the data collection, which occurred in April and May 2009, the semi-structured in-depth interview technique was used, recorded on an electronic device. The length of each interview varied between 30 minutes and 1 hour. All participants were capable of interacting with the researcher, as well as answering the questions. Next, the interviews were transcribed and analyzed for their thematic content<sup>(7-8)</sup>.

## Description and discussion of results

In the process of analysis 2843 units of analysis (UA) were identified, distributed in 265 themes, resulting in six categories, which are presented below.

### Memory elements of the anchoring of AIDS in society and its transformation process

One of the anchors of AIDS presented related to two social groups, homosexuals and promiscuous people. Therefore, there is still a predominance of the representation associated with the so-called risk group, although this concept has already been replaced by

that of vulnerability, as previously highlighted<sup>(3,9)</sup>. The origin of AIDS, for the social actors of the study, was attributed to foreign countries, especially to Africa and to the African monkey, considering the possibility of men having had intercourse with these animals. Furthermore, even the development of the AIDS virus in a laboratory was mentioned and was associated with the plague and syphilis. The study demonstrated that the anchoring process that occurred early in the epidemic remains present in the social discourse in current times. The subjects exhibited such concepts referring to their social memories, in the midst of which remains a set of representations that circulate in society and configure some of the characteristics of their representations, namely, to be influenced by the media in their cognitive reconstruction.

Another anchoring process present in the representations of this group reaffirms the connection of AIDS with diabetes, configuring the syndrome as a chronic, non-fatal disease that can be controlled with drugs available through governmental programs. In a certain way, the representation of death is overcome and replaced by a space for the representation of life and of survival, as expressed in the following quote: *I take my medicine every day and get on with life. For me it is like being a person who has diabetes or other diseases and so you are required to take the medication* (subject 1).

### **Transmission and Prevention of AIDS according to the people living with HIV**

The protagonists of this study presented almost all of the scientifically proven ways regarding the means of HIV transmission, such as: blood transfusion, contact with wounds and/or bodily fluids, sexual relationships, cutting and piercing material and work accidents, characterizing the reified universe of the representations. The subjects said they had sometimes adopted compromising sexual behavior, which culminated in their seropositivity, demonstrating a strong sense of guilt. The themes that follow describe this situation: *I did not prevent it/I did not use condoms; I engaged in dubious behavior/I took risks; I had sex with men and women/I had multiple partners; I thought that condoms were like sucking a candy that was still in its wrapper. The following statement portrays this reality. I had a very sexually active life. I went out with several partners, before I found out. I had several partners. When I knew, I already had a steady partner, I was already living with him, and I stayed with him, but also I did not tell him. We stayed together for seven years, and we never used condoms, I hid when I found out. I still did not say anything to him* (subject 2).

In relation to condom use, the problem becomes more visible when related to people with stable relationships. It was observed in another study that, in stable relationships where trust exists between the partners, condom use is judged to be unnecessary, because they feel safe from the risk of HIV infection. The study also indicates the perpetuation of the concept of the risk group, making them believe, consequently, that they are immune to HIV infection<sup>(10)</sup>. The interviewees in the present study made similar statements. One reflection of this thinking is encountered in the theme "I thought it would not happen to me" expressed by 70% of respondents. *They think that: ah! this will never happen to me! Like me in my case. Ah! this will never happen to me! I am a married woman, a decent, correct woman. I married my first boyfriend, that whole thing... So I thought it could not happen to me. However it happened, right?* (Subject 3).

An important change in the way of thinking about HIV/AIDS occurred in the 90s, where it was sought to overcome the contradiction between "risk group" and the "general public", moving from the notion of individual risk to a new perception of social vulnerability, crucial not only for the perception of the dynamics of the epidemic, but for any strategy that can reduce its advance<sup>(3,11)</sup>.

### **The quotidian life of seropositive people permeated by the process of vulnerability to HIV**

The recognition of the individual vulnerability when faced with HIV influences, above all, the human practices and behavior. Therefore, to obtain concrete information about HIV/AIDS regarding the means of transmission and prevention positively favors combating the epidemic<sup>(9)</sup>. The content addressed by the subjects were varied, however some points were emphasized, considering their individual and social consequences. Among these: Ignorance of not knowing what it was, lack of information and lack of knowledge, I had no feelings, I never thought about it, I did not worry and ignored the issue.

In this sense, one of the problems of the concept of risk behaviors is that prevention work is replaced by a culpable and individualistic perspective. If a person is infected with HIV, it is because they adopted risk behavior, hence the "fault" is theirs. In this case, the fact that the modes of transmission of a disease sometimes have reasons which are more social than individual are not taken into account. Therefore, these issues are not resolved by seeking to blame people for attitudes held or by labeling individuals as role models, but rather, by

comprehending the motives that condition people and groups that are in situations which make them more vulnerable to HIV infection<sup>(12)</sup>.

Among the interviewees there also appeared the representation of the individual vulnerability, in which they considered that all people are susceptible to acquiring HIV. The themes that reflect this perception are: AIDS has spread to most Brazilians; both in the poor and in the rich; and anyone can contract it nowadays, married women, the elderly, and children (already born). These themes, however, were expressed by a small group of interviewees, which may indicate a representational subgroup in relation to the vulnerability and the individual and social risks related to the syndrome.

Although the subjects reported other population groups in the scenario of HIV/AIDS, it was noted that the representation of the risk group remains present and strong, because there are people who are constantly mentioned when discussing the greatest risk of acquiring HIV, which are the homosexuals, the promiscuous and drug users, according to the following report: *The only people who have this kind of disease are homosexuals, they are depraved people* (subject 4).

### Discrimination and concealment in living with HIV

Seropositive people present the concealment of the disease as a strategy for social survival. Thus, they can continue life as normal people without being accused or discriminated against, either within the family, social or work environments. In the latter, the concealment of HIV is a way to maintain the job, since, having their secret revealed, the individuals run the risk of suffering prejudice.

The themes that portray the process of concealment were varied, among them: People who are seropositive try to hide/are ashamed; My family does not know, My friends do not know/ people do not know; I do not say to spare my parents; I do not suffer prejudice because people do not know (they treat me as an equal); I do not speak about it to spare me, there are people who pretend they do not have the disease, at work if you say someone is seropositive they are fired; and people get along with me without knowing I have the disease.

It was observed that these individuals find it difficult to feel socially accepted, therefore the omission of seropositivity is justified by the fear of being judged. In this context, AIDS, to the deponent that follows, can be seen as "punishment" and that "the person did something to deserve it" because they would be among those belonging to the "risk group". Thus, the image of

AIDS remains directly associated with deviant behavior. *Seropositive? The word is hidden. It's kind of hidden to be seropositive, it is very difficult, no one can say that you are seropositive if you are not to be discriminated against, you feel discriminated against, you're diseased, you're a prostitute, you're a shameless travesty. Outsiders think the person who has AIDS deserved it. Ah! he had too much sex, he took cocaine, he used intravenous drugs, he's paying for what he did* (subject 5).

Seropositive people opt for concealment of the serology, considering that HIV has, in its metaphorical history, a moral and reprehensible judgment that interferes in the private life. This reveals an obscure, illicit side and exposes the bodily pleasures that exceeded, in most cases, the social control<sup>(13)</sup>. In general, the socially elaborated negative representations referring to those living with HIV/AIDS are reinforced by the language and the metaphors used to talk and think about HIV and AIDS. This process increases the fear and, above all, the isolation of those affected. Furthermore, the stigma is extended to the family and friends<sup>(14-15)</sup>.

However, the experience and knowledge gained has led these people to adopt a different view when it comes to those infected with HIV. A change was noticed in the attitudes and practices toward seropositive people, due to not incorporating the prejudice to the discourse after being diagnosed and to living with HIV in their quotidian. However, the biased attitude of society imposed on seropositive people prejudices them substantially, causing serious disorders, such as social isolation, loss of the will to live and therefore to seek stimuli for treatment. The prejudicial acts also lead to processes related to the decrease of self-esteem and the difficulty of developing an emotional relationship.

In this sense, stigma is a term used in reference to an deeply derogatory attribute and can also be considered a defect, a weakness or a disadvantage, constituting a specific discrepancy between the virtual social identity and the actual social identity<sup>(16)</sup>. As a consequence, the study subjects presented a tendency to withdraw from or guard themselves against the social life after the discovery of the diagnosis. In the expression *would not be able to have more relationships with people* (subject 6), an image of isolation can be observed as something already determined by society or as a form of punishment for having contracted HIV.

The social stigma and prejudice are attitudes stimulated, above all, by the fear of contagion and the lack of information, and these raise discomfort and suffering in seropositive people who are targets of social contempt. The themes that reflect this representation

are: the people keep away, they avoid you, I don't have the same friendship; people do not get close, they avoid any physical contact (handshake, kiss on the cheek).

Thus, an alternative presented by some social actors of the study to cope with such a situation was to seek relationships with other seropositive people like them, connoting the idea that there are two distinct groups, "different with different" or "the same with the same".

### **The process of adherence to treatment in the quotidian of seropositive individuals**

Although AIDS is an incurable disease, there are now treatments that increase the expectation and the quality of life of people living with the disease. It was observed that one of the great motivators of adherence, in this scenario, is the fact that the users believe in the positive outcome of therapy. However, for the subjects, a dichotomy exists around the therapy. After HIV, life and health depend on the use of medication and on treatment and therefore, the abandonment of these ultimately leads to disease progression and, consequently, death. Self-care is also related to living long and well, and the lack of it, likewise, results in disease and death. The perceptibility regarding the aims of the treatment becomes a favorable factor in the adherence to antiretrovirals.

The interviewees demonstrated that they comprehend the importance of the correct use of antiretrovirals, but there are various factors that influence the appropriate use of these medications, often leading to the abandonment of the treatment. It was identified that one of the motives leading to such an attitude is related to the side effects of these drugs, especially the change in body image due to lipodystrophy that can lead to their characterization of seropositive people as having the "AIDS look".

Given this context, effective strategies must be developed to guide and advise so that professionals can evaluate, discuss and raise awareness about the individual living with HIV/AIDS in their daily routine, considering the socioeconomic and cultural conditions that may prevent or limit the treatment, to then be able to define with this subject measures that can facilitate the process of therapeutic adherence<sup>(17)</sup>.

It was also observed that the subjects presented a tendency to naturalize living with HIV when stating: Begin to live normally/ "it's a piece of cake" / I have no problem. These cognitive constructions were not perceived as an escape from the situation, but as an adaptation and acceptance of the seropositivity and

of the antiretroviral treatment. The statements were complemented with the daily reality concerning the care needed to live well and consequently to reduce their vulnerability to illness. This conjecture suggests that the interviewees were conscious of the treatment, considering that it is for the rest of their lives, similar to a chronic disease such as diabetes.

It was perceived that this process of naturalization has been linked to treatment success. However, this depends above all on discipline and requires some care actions, which encourage the incorporation of healthy habits in the daily routine, such as sleeping early, eating well, doing physical exercise, not drinking alcohol, not smoking and maintaining a balanced diet.

It should be noted that religion and faith made up part of the quotidian life of most of the subjects studied and are considered as defenses and support for coping and accepting the seropositivity, as well as for facing the quotidian reality including the social life. However, it is emphasized that religion can often lead them to withdraw from the therapy because they believe they are or will be cured.

### **Coping with the quotidian experienced for the subjects living with HIV**

Part of this category was shaped linked to the themes, negative feelings related to AIDS, and AIDS related to death. The other themes provide the practical dimension of these feelings, such as fear of rejection, of AIDS and of death, depression, I wanted to kill myself, hopelessness, always crying and depression, among others. It was observed that the first impact of the diagnosis for the subjects was a direct relationship of AIDS with death. For them, AIDS was the end and this positive result represented their fatal sentence. However, the following statement demystifies AIDS as death: *At first it was a monster, so I thought it would kill me immediately, but then I saw that it is nothing like that* (subject 7). Therefore, a tendency was observed of a representation of AIDS linked to life and to new perspectives, overcoming, at least in part, its representation as death.

The representation of imminent death is present at the moment of diagnosis, considering that this is the moment of confrontation with the situation bordering between life and death. After the contact with health professionals and other seropositive people, coupled with the absence of symptoms, death ceases to be as immediate as imagined<sup>(18-19)</sup>. However, the confirmation of the fragility of life becomes the center of everything, because they do not know how to act

and this confrontation with a non-concrete reality can generate enormous suffering. This suffering becomes real when the subject encounters an irreversible reality, due to AIDS being incurable, which determines negative feelings centered on the fear of AIDS, of death and of rejection, as well as linked to other feelings, such as anxiety and sadness.

Given this context, diverse ways that seropositive people envisage life after HIV were noted, as well as the expectations of life faced with the syndrome. Among these, the group mentioned the need to seek information about HIV/AIDS after the diagnosis. It should be noted that this is a new world in which these subjects have become part, having come to learn about the disease and to comprehend how the treatment contributes to the process of acceptance and the overcoming of various fears (such as death) sometimes experienced in the first moments after the diagnosis, organizing the quotidian life. In this sense, it is important for them to comprehend their current state, which is a facilitator in the development of skills to manage self-care in the context of their daily routine in a conscious way, especially in the process of adherence to the antiretrovirals.

Themes were also perceived in the statements related to the social support network, such as the family, partner and friends that are important in the construction of a supportive and caring quotidian. For the people living with HIV/AIDS, these friends (usually the most intimate) do not have prejudiced attitudes, they seek help or simply accept them without prior judgment. It is noteworthy that only 20% of the participants reported support from the family after the serological revelation. It is understood that the support of both family and friends is essential for facing and overcoming the disease, especially in the adherence process.

### Final considerations

The results show a complex social representation regarding AIDS and its impact on the quotidian of seropositive individuals, particularly in the process of group insertion, of social integration, of stigmatization, of adherence to therapy and of living with the virus and/or the syndrome. This representation, far from being just an imaginary reconstruction regarding an object, presents itself as a modulator of the lived reality and an operator of the situations faced. It has also been observed that vulnerability is related to objective questions, such as access to information, for example, and subjective questions, such as the personal empowerment in the

face of social and cultural situations. This construction presents itself as a key piece in combating the epidemic, both in regard to the construction of policies covering this subjectivity, producing an impact on individual and intimate decisions, as well as in the transfer of information which is not only true from the scientific standpoint, but also makes sense for the subjects and provides adherence to their quotidian.

The understanding, on behalf of the nurse, of the contents of this representation, as well as of its dynamicity, will allow their actions, especially educative ones, to have more relevance in the life and the quotidian of seropositive individuals. It is believed that these will be effective due to the fact that human beings do not live exclusively using their rational capacity, but are mainly influenced by their worldview and symbolic comprehension of the facts.

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