# THE STIGMA OF HIV POSITIVE USERS OF THE PUBLIC HEALTH SYSTEM

# O ESTIGMA DE USUÁRIOS DO SISTEMA PÚBLICO DE SAÚDE BRASILEIRO EM RELAÇÃO A INDIVÍDUOS HIV POSITIVO

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#### ARSTRACT

Introduction: The initial idea of AIDS as a disease that affects individuals with attitudes disapproved by society has caused stigmatization and prejudice among HIV positive individuals. Objective: To analyze the existence of prejudice and discriminatory attitudes of Unified Health System ("Sistema Único de Saúde" - SUS) users towards HIV positive individuals, according to socioeconomic class. Methods: This is a cross-sectional, descriptive research, with quantitative approaches. We categorized the population according to the Brazilian Criterion of Economic Classification, and applied a structured questionnaire related to prejudice, discrimination, and perceptions regarding sterilization and infectious diseases; as well as questions from a relevant Ministry of Health publication. Results: The study population consisted of 150 individuals, 77.3% of which asserted they would agree to be treated immediately after an HIV positive patient and 92% after a prisoner. However, 42% preferred being examined before HIV positive individuals, and 23.3% before a prisoner. The majority reported concern about the sterilization of dental material (98%), though 42% did not know how the procedure was carried out. There was significant difference between individuals who initially said they would not mind being received after HIV positive patients (p=0.0029) or inmates (p<0.0001), and those who later said they would rather be received before individuals in these conditions. There was no association between socioeconomic class and prejudice. Conclusion: SUS users show prejudicial and discriminatory attitudes toward HIV patients, often expressed in subtle manners, regardless of economic class of the individual.

Keywords: discrimination; HIV positive; acquired immunodeficiency syndrome.

#### RESUMO

Introdução: O conceito inicial de que a AIDS era uma doença que ocorria em indivíduos com atitudes desaprovadas pela sociedade causou estigmatização e preconceito em indivíduos HIV positivo. Objetivo: Analisar a existência de preconceito e atitudes discriminatórias de usuários do Sistema Único de Saúde (SUS) em relação a indivíduos soropositivos, considerando sua classe socioeconômica. Métodos: Trata-se de uma pesquisa descritiva, com caráter transversal e abordagem quantitativa. Aplicou-se o Critério de Classificação Econômica Brasil, para a classificação econômica da população, e um questionário estruturado com questões relacionadas ao preconceito e à discriminação, à percepção sobre esterilização e ao contágio de doenças; além de questões de manual do Ministério da Saúde que aborda o assunto. Resultados: A população estudada foi composta por 150 indivíduos, dos quais 77,3% afirmaram que aceitariam ser atendidos após um paciente soropositivo, e 92%, após um presidiário. Entretanto, 42% prefeririam o atendimento antes de um indivíduo soropositivo, e 23,3%, antes de um presidiário. A maioria relatou preocupação quanto à esterilização do material odontológico (98%), embora 42% não soubessem como o procedimento ora realizada. Existiu diferença significativa entre os indivíduos que inicialmente afirmaram aceitar o atendimento após um paciente HIV positivo (p=0,0029) ou um presidiário (p<0,0001) e os que posteriormente disseram preferir o atendimento antes. Não houve associação entre classe econômica e preconceito. Conclusão: Os usuários do SUS apresentam preconceito e atitudes discriminatórias em relação a pessoas soropositivas, expressa, às vezes, de maneira velada, independentemente da classe econômica do indivíduo.

Palavras-chave: preconceito; soropositividade para HIV; síndrome da imunodeficiência adquirida.

### INTRODUCTION

In the early 1980s, the first AIDS cases were reported in the United States, showing clinical characteristics of immune system impairment in male homosexual patients, raising suspicions about a relation between homosexuality and the disease. (1)

AIDS was conveyed through the media as a lethal and incurable illness(1) associated with homosexuals, drug users and sex workers, reinforcing the stigmatization of these groups by all strata of society, regardless of educational level and knowledge on the epidemic, raising fear and distrust among the population<sup>(2)</sup>.

The subsequent spread of the disease among heterosexuals, children and infants revealed that the idea of a homosexual risk group was mistaken(1). Today, we can see the progression of the AIDS epidemic and the human suffering caused by stigma,

inequity. (3). For this reason, asymptomatic individuals often do not reveal their condition.(2) The term "stigma" was created by the ancient Greeks to refer to bodily traits that manifested because of an individual's unworthy

prejudice, and discrimination, which are processes of devalua-

tion and intolerance towards those individuals, causing social

moral behavior. Thus, people considered "normal" often promoted discriminatory attitudes against individuals who bore some difference unaccepted by society(4). The stigma attached to HIV goes far beyond individual effects, and is directly linked to the reproduction of social inequalities, leading to prejudice, rejection and loss of *status*<sup>(5)</sup>.

In turn, prejudice is a form of thought in which a person reaches conclusions which pre-judge another person, leading to discrimination(6).

Studies show reports of sick individuals who were denied professional treatment after revealing they had HIV, or after manifesting some of the disease's clinical characteristics<sup>(1,2)</sup>. However, few studies have tried to identify the different forms of prejudice shown by public health system users towards individuals with HIV.

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## **OBJECTIVE**

To verify the existence of prejudicial and discriminatory attitudes of users (in different economic classes) of the Unified Health System (SUS) towards HIV-positive patients, in a city in Northwestern São Paulo State, Brazil.

## **METHODS**

The research was approved by the Human Research Ethics Committee of the School of Dentistry of Araçatuba, Universidade Estadual Paulista "Júlio de Mesquita Filho", within the standards required by Resolution no. 466/12.

This is a cross-sectional, descriptive research, with quantitative approaches. Initially, the city Secretary of Health was contacted to be informed about the study's objectives, in order to obtain support for the conduction of the research.

Participants were users of "basic health units" (BHU) of Américo de Campos, in Northwestern São Paulo State.

Previously, a pilot study was conducted on 10 patients with the purpose of verifying the need to rectify the questionnaires.

Data collection took place on an individual basis, in a private room at the only BHU of the city, on the same day as patients' appointments, and every day from July to October, 2014.

All patients who attended the BHU during the collection period were invited to participate in the research. Those who agreed signed the Informed Consent Form (ICF) and responded to two questionnaires, applied by a trained researcher:

- 1. the Brazilian Economic Classification Criteria (for short, BECC, or "Critério de Classificação Econômica Brasil"), drafted by the Brazilian Association of Research Companies, (7) as a way to categorize the population: in this scale, the educational level of the head of the household is worth 0 to 8 points; the remaining points are provided by the amount of durable consumer goods owned by the family (vehicle, color TV, radio, refrigerator, freezer, washing machine, etc.); the number of rooms and bathrooms in the house and the number of maids working in the house. The sum of these indicators divides the population in several classes, "Class A1" (from 42 to 46 points) being the highest, and "Class I" (from 0 to 7 points) the lowest; and b);
- 2. a questionnaire on stigma and discrimination, with questions from the Ministry of Health's Knowledge, attitudes and practices survey of the Brazilian population<sup>(8)</sup>. Additionally, questions regarding: the acceptability of being treated by an HIV-bearer dental surgeon; the perception of the possibility of acquiring diseases at the dental office; the relative infectiousness between HIV and hepatitis; the concern for cleanness and sterilization of the equipment used by dental surgeons; the acceptability of being treated after patients with AIDS or inmates; and whether respondents would prefer, given the choice, to be treated before HIV patients or prisoners.

As a number of penitentiaries are present in neighboring towns, inmates receive dental treatment at the city's public health units, justifying their inclusion in the research. Studies show a high rate of prison inmates with sexually transmitted diseases (STDs), such as HIV and syphilis, in addition to drug injection and history of blood transfusion, fostering discriminatory attitudes against these groups<sup>(9)</sup>.

Collected data was handled using the *Epi Info<sup>TM</sup>* 7 software and presented as absolute and relative frequencies. Statistical analysis was performed using the test for comparing two proportions as well as the  $\chi^2$  test with 5% significance level, using the *BioStat* 5.0 software<sup>(10)</sup>.

### RESULTS

The population studied consisted of 150 users of the public health system, of which 74% were female; 31.3% were aged between 18 and 27 years, 17.3% between 28 and 37 years, 20% between 38 and 47 years, 16.7% between 48 and 57 years and 8% were older than 58 years. By BECC, the population was divided into economic classes: 10% belonged to class A2, 22% to class B1, 37.3% to class B2, 22.7% to class C1, 6.7% to class C2 and 1.3% to class D1.

Forty percent of the respondents reported having suffered some form of discrimination, due to color or race (0.7%); gender (6.7%); social condition and lack of money (22.7%); sexual orientation (4%); profession or occupation (12.7%); or HIV diagnosis, if applicable (3.3%); due to illness or disability (6.7%); age (12%); physical appearance (12.7%); or other reasons (14%).

Also, 32.7% of respondents said they did not agree with the adoption of children by homosexual couples; 13.3% said they would not have homosexual friends; 91.3% thought that if a person had AIDS, he or she should receive treatment at home; 24.7% asserted they would stop buying vegetables if the vendor was revealed to be infected with HIV; 8.7% believed that a teacher with the AIDS virus should not continue to give lessons; 38% believed that, if a family member was infected with HIV, the family should keep this a secret; and 5.3% claimed knowing someone close with HIV or who died of AIDS.

23.4% said they would not agree to receive treatment from a dental surgeon infected with HIV; 86% believed infections could be acquired at the dental office; and 80.7% thought that HIV easier to contract if compared to hepatitis B. In addition, 98% showed concern about the sterilization of the dental surgeon equipment, although 42% did not know how this procedure was performed.

77.3 and 92% reported agreeing to receive treatment after a patient with HIV or an inmate, respectively. However, when questioned whether they would prefer being treated before or after an individual with AIDS or an inmate, 42 and 23.3%, respectively, answered "before." A statistically significant difference was observed, by comparing the ratios, between individuals who initially said they would accept being treated after a patient with HIV (p = 0.0029; power=0.8672) or an inmate (p<0.0001; power=0.9970) and those who later said they would prefer being treated before (**Tables 1 and 2**). There was no statistical relation between economic classes and the prejudice revealed by the preference of being treated before an individual with AIDS (p=0.1036) or an inmate (p=0.6034) (**Tables 3 and 4**).

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### DISCUSSION

The prevention of HIV/AIDS and hepatitis is a crucial aspect in dentistry; therefore, preventive measures should be used during treatments<sup>(11)</sup>. A survey of dentistry students revealed they represent the main danger to the patient, as they tend to neglect the importance of cleaning and disinfecting materials and equipment used during the procedure<sup>(12)</sup>, highlighting a flaw in the training of future professionals. In our study, many people showed concern for the cleanness and sterilization of materials used during dental treatment, but did not know how the process was carried out.

Furthermore, the risk of contracting HIV is much lower than that for the hepatitis virus, with estimates of 0.3% for HIV, 1 to 10% for hepatitis C and 40% for hepatitis B.<sup>(13)</sup> However, the present study shows that many respondents held inaccurate views regarding the transmission risks of these viruses. Rather, they were more concerned with the cross-transmission of HIV, as it causes an incurable disease, affects one's quality of life and leaves visible marks that lead to prejudice<sup>(11)</sup>.

The different forms of stigma and discrimination related to AIDS occur due to the disease's characteristics, and cause great impact on people's lives, (14) resulting in self-stigmatization, in which case individuals tend to accept society's negative beliefs about them and isolate themselves from social life. Self-stigmatization is considered the most difficult stigma to overcome<sup>(15)</sup>. In turn, relatives and those who are closest to patients suffer from what has been called a "co-stigma", receiving the same treatment as infected individuals and being excluded from society<sup>(16)</sup>.

Therefore, patients' families are often not a center of support; but rather a focus of stigmatization, discrimination and exclusion<sup>(17)</sup>. In our study, many people believed that a family member's HIV infection should be kept a secret, probably due to the exclusion suffered by both the infected person and their relatives and closest friends through the co-stigma. This may have led to fewer people reporting to know someone who is HIV positive.

**Table 1 –** Comparison between the proportion of individuals who initially said they would agree to being examined after an HIV-positive patient and those who later said they preferred being examined beforehand. Américo de Campos, 2014.

	Initial agreement							Later preference						
Y	Yes		No		Total		Irrelevant		Before		Total			
n	%	n	%	n	%	n	%	n	%	n	%			
116	77.3	34	22.7	150	100	87	58	63	42	150	100			

P=0.0029.

**Table 2 –** Comparison between the proportion of individuals who initially said they would agree to being examined after an inmate and those who later said they preferred being examined beforehand. Américo de Campos, 2014.

	Initial agreement							Later preference						
Ye	Yes		No		Total		Irrelevant		Before		Total			
n	%	n	%	n	%	n	%	n	%	n	%			
138	92	12	8	150	100	115	76.7	35	23.3	150	100			

P<0.0001.

**Table 3 –** Comparison between economic class and preference for being examined before HIV-positive individuals. Américo de Campos, 2014.

Preference for examinations before HIV-positive patients									
Economic	Be	fore	Irrel	evant	Total				
class	n	%	n	%	n	%			
A2	8	5.3	7	4.7	15	10			
B1	15	10	18	12	33	12			
B2	20	13.3	36	24	56	37.3			
C1	11	7.3	23	15.3	34	23.6			
C2	7	4.7	3	2	10	6.7			
D1	2	1.4	0	0	2	1.4			
Total	63	42	62	58	150	100			

P=0.1036

**Table 4 –** Comparison between economic class and preference for being examined before inmates. Américo de Campos, 2014.

Preference for being examined before prisoners									
Economic	Be	fore	Irrele	evant	Total				
class	n	%	n	%	n	%			
A2	5	3.3	10	6.7	15	10			
B1	10	6.7	23	15.3	33	22			
B2	11	7.3	45	30	56	37.3			
C1	6	4	28	18.6	34	23.6			
C2	2	1.4	8	5.3	10	6.7			
D1	1	0.7	1	0.7	2	1.4			
Total	35	23.4	115	76.6	150	100			

P=0.6034.

Many individuals choose not to reveal their true diagnosis, fearing embarrassment and various distressing feelings such as fear, shame, stigma and social isolation<sup>(18)</sup>. According to a survey conducted in Mozambique, several women who lived with HIV were afraid to disclose their condition, for different reasons, against a strong discriminating environment in which AIDS raises moral objections and is associated with death. These women worked hard in concealing their diagnoses, even among relatives, retreating from social relations as a way to protect themselves and preserve their family members and acquaintances. In their situation, disclosing their condition would mean losing their identity, being seen by society as "discreditable" and doomed to death<sup>(17)</sup>.

In our study, most respondents reported suffering some type of discrimination throughout their lives, due to their color or race, gender, social status, sexual orientation, profession, disease, age or physical appearance. Stigma and discrimination cause low self-esteem, depression, psychiatric disorders, post-traumatic stress disorders, and stress, affecting the individuals' mental health due to insults and social exclusion. Another study, conducted in South Africa and China, showed that people with HIV had feelings that may lead to suicide<sup>(14)</sup>.

Prejudice against homosexuals is still strongly related to AIDS, even though the disease is widely spread among heterosexual individuals nowadays<sup>(2)</sup>, showing that the knowledge about HIV is insufficient. The lack of knowledge regarding contamination and risk transmission of HIV means people's views are grounded on myths, beliefs, emotions and folk discussions distant from scientific knowledge. (19) This is shown in the present study, in which people associate homosexuality with promiscuity and a greater risk of acquiring AIDS.

Aware of this reality, the Ministry of Health makes great efforts to spread information on the disease through the National STD/AIDS Program<sup>(8)</sup>, providing data on its true transmission risks and prevention measures. This information is reaching the population, as demonstrated in a study with adolescents who reported believing that the most common form of HIV transmission is through unprotected sexual intercourse and by sharing needles among injectable drug users<sup>(20)</sup>.

Health professionals, especially dental surgeons, due to fear and ignorance about the disease's transmission mechanisms, are often unwilling to treat HIV-infected patients<sup>(1)</sup>. Discrimination and prejudice on the part of health professionals toward HIV-positive patients are commonly reported. That is especially the case for dental surgeons, who reportedly refuse treatment by fear of contracting pathogens during procedures<sup>(2,11)</sup>.

Refusals happen less often as dental surgeons' knowledge regarding the risks of occupational infection increases, and among those who are familiar with the protocols of post-exposure to biological materials and thus maintain their equipment adequately sterilized<sup>(21)</sup>. Confirming this, the present study observed prejudice and discrimination on the part of patients who would not accept being treated by a professional with HIV. This highlights the importance for the general population to have access to adequate information on the matter, so as to minimize or eliminate discriminatory attitudes and practices.

Our research also revealed that part of the respondents would prefer being treated before inmates, due to the stigma revolving around this population. It is estimated that 20% of Brazilian prisoners are infected with HIV, a scenario that results from prison overcrowding, with substandard and insanitary cells – an environment prone to the spread of epidemics and infectious diseases, mainly through homosexual relations, sexual violence, and the use of injectable drugs<sup>(22)</sup>.

Prejudice, sometimes, is not shown explicitly; in a survey that asked adolescents about the forms of discrimination, one of the answers was: "[It's] not that I do anything, I don't go as far as excluding people or mistreating them, but I'm always a bit wary." Remarks like this show that prejudice is not always evident, but is also expressed in more subtle ways<sup>(23)</sup>. This probably happens due to the fear of punishment, as Brazilian law forbids any form of discrimination<sup>(24)</sup>. According to Law no. 12,984, discrimination against HIV carriers or AIDS patients is a crime, punishable by up to four years in prison and a fine<sup>(25)</sup>. In our research, this reason may have initially led respondents to show less prejudice (when asked about how comfortable they were to be examined after HIV patients or inmates) than when asked the question later.

Among different economic classes, there was no statistically significant relation between those who preferred to be treated before inmates or patients suffering from HIV, and those who were indifferent, revealing the existence of a subtle prejudice throughout the whole population, regardless of economic class, probably due to the possibility of legal sanctions.

Further studies should be carried out with larger populations, so as to confirm the existence of different forms of discrimination by public health system towards HIV-positive individuals.

#### CONCLUSION

The data obtained in this study suggests that the SUS users of the city analyzed (regardless of economic class) show prejudice and discriminatory attitudes toward people with HIV, that often manifest subtly.

#### **Conflict of interests**

The authors declare no conflict of interests.

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