



## People living with the human immunodeficiency virus: perception of dental care

### *Pessoas vivendo com o vírus da imunodeficiência humana: percepção sobre atendimento odontológico*

### *Personas que viven con el virus de la inmunodeficiencia humana: percepción de la atención odontológica*

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#### ABSTRACT

**Objective:** To assess the perception people living with the human immunodeficiency virus have in relation to the occurrence of discriminatory attitudes during dental care. **Methods:** This is a qualitative study conducted with people living with the human immunodeficiency virus undergoing treatment in a reference center in the city of Governador Valadares, Minas Gerais, Brazil, from January to July 2019. The study included 25 participants, and semi-structured interviews were carried out. The collected data were subjected to Thematic Content Analysis and the categories that emerged included fear of disclosing the diagnosis to the health care professional and health care professionals' refusal to provide care. **Results:** Among the interviewees, there was a perception of trust in disclosing serological status to the professional, but there were also some who hid it. Certain insecurity was noted in dentists while delivering dental treatment, and there were some discriminatory attitudes in the office and even refusal to deliver care. **Conclusion:** There was a perception of discriminatory behavior and difficulties in obtaining dental care among the people living with the human immunodeficiency virus analyzed in the present study. In addition, there was fear of disclosing the diagnosis to the dentist, and some hid it.

**Descriptors:** AIDS Serodiagnosis; Dentistry; Social Discrimination.

#### RESUMO

**Objetivo:** Avaliar a percepção da pessoa vivendo com o vírus da imunodeficiência humana sobre a ocorrência de atitudes discriminatórias em atendimento odontológico. **Métodos:** Trata-se de um estudo qualitativo, realizado com pessoas vivendo com o vírus da imunodeficiência humana e em tratamento em um centro de referência, na cidade de Governador Valadares, Minas Gerais, Brasil, no período de janeiro a julho de 2019. Foram incluídos 25 participantes no estudo, tendo sido realizadas entrevistas semiestruturadas. Os dados coletados foram submetidos à análise de conteúdo temática e, a partir daí, as categorias que emergiram incluíram o receio da informação do diagnóstico ao profissional de saúde e a recusa de atendimento por profissionais da saúde. **Resultados:** Entre os entrevistados, houve percepção de confiança para informação de sua condição sorológica ao profissional, embora também tenha ocorrido omissão dela. Foi percebida certa insegurança relacionada ao cirurgião-dentista na realização do tratamento odontológico, incluindo atitudes discriminatórias no consultório e até recusa de



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atendimento. **Conclusão:** Entre as pessoas vivendo com o vírus da imunodeficiência humana investigadas no presente estudo, houve percepção de condutas discriminatórias e dificuldades para conseguirem atendimento odontológico, além do receio de informar seu diagnóstico ao cirurgião-dentista, omitindo-o.

**Descritores:** Sorodiagnóstico da AIDS; Odontologia; Discriminação Social.

## RESUMEN

**Objetivo:** Evaluar la percepción de la persona que vive con el virus de la inmunodeficiencia humana sobre la ocurrencia de actitudes de discriminación durante la atención odontológica. **Métodos:** Se trata de un estudio cualitativo realizado con personas que viven con el virus de la inmunodeficiencia humana y en tratamiento en un centro de referencia de la ciudad de Governador Valadares, Minas Gerais, Brasil, en el periodo entre enero y julio de 2019. Se ha incluido 25 participantes en el estudio utilizándose de entrevistas semiestructuradas. Se ha realizado el análisis de contenido temático de los datos recogidos de los cuales emergieron las categorías que han incluido el miedo de la información del diagnóstico para el profesional sanitario y el rechazo de la atención de parte de los profesionales sanitarios. **Resultados:** Entre los entrevistados, hubo la percepción de confianza para dar la información de su condición serológica al profesional aunque también haya ocurrido la omisión de información. Se ha percibido cierta inseguridad relacionada al cirujano-odontólogo para la realización del tratamiento lo que incluye las actitudes de discriminación en el consultorio hasta el rechazo de la atención. **Conclusión:** Entre las personas que viven con el virus de la inmunodeficiencia humana investigadas en el estudio, hubo la percepción de conductas de discriminación y dificultades para conseguir la atención odontológica además del miedo para informar su diagnóstico al cirujano-odontólogo, omitiéndolo.

**Descriptor:** Serodiagnóstico del SIDA; Odontología; Discriminación Social.

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## INTRODUCTION

With the progress of knowledge, the decrease in mortality caused by the human immunodeficiency virus (HIV) has improved since its identification. More than 36 million people worldwide are currently living with HIV, the majority living in sub-Saharan countries<sup>(1)</sup>. In Brazil, 300,496 cases of HIV infection were reported between 2007 and June 2018, and from the beginning of the epidemic in the 1980s until June 2019, there were 966,058 cases identified<sup>(2)</sup>. The depletion of CD4 T lymphocytes and a consequent immunosuppression, which are characteristics of the presence of HIV in the body, have been extensively studied, including in the Brazilian population<sup>(3)</sup>.

Although advances in diagnosis and antiretroviral therapy have altered the clinical and epidemiological characteristics of the disease and significantly increased life expectancy of individuals undergoing treatment<sup>(4)</sup>, people can still suffer prejudice and stigma in social life and in health care facilities. Discrimination in health care can occur through three main forms: the refusal of care by professionals after the disclosure of the serological condition, extra measures of biosafety, or other discriminatory attitudes that may include interventions that would not be indicated to other patients<sup>(5)</sup>.

Stigma is seen as a disadvantage attributed to people with some difference that is perceived as a defect or weakness which society uses to disqualify them. Thus, the stigmas of a person or group can provoke behaviors such as disgust, detachment, or violent reactions<sup>(6)</sup>. Since the emergence of the epidemic, prejudices related to sexuality and gender of people living with the human immunodeficiency virus (PLHIV)<sup>(7)</sup> have been constructed.

In Brazil, health care has legal, ethical, and biological support, but there is still an indisposition of professionals in providing care to HIV-positive people, which supports discriminatory attitudes<sup>(8)</sup>. Article 6 of the National Health Promotion Policy (*Política Nacional de Promoção da Saúde – PNPS*) highlights the importance of promoting equity and improving conditions and ways of living so as to expand the potential of individual and collective health and reduce vulnerabilities. Thus, the importance of integrated actions and interventions towards the social determinants of the disease process should be emphasized<sup>(9)</sup>.

In that regard, the importance of providing comprehensive health care to PLHIV should be highlighted, and it should include oral health due to the greater propensity for opportunistic diseases and the presence of oral manifestations that may be the initial signs of infection by the human immunodeficiency virus (HIV). Some diseases, such as oral candidiasis, oral hairy leukoplakia, Kaposi's sarcoma, and gingival linear erythema, in addition to suggesting infection, may indicate progression to acquired immunodeficiency syndrome (AIDS). Also, in this group of patients, the frequency of periodontal diseases reinforces the importance of oral health care and assistance<sup>(10)</sup>.

Within this context, the perception people living with the human immunodeficiency virus have regarding the occurrence of discriminatory attitudes in oral health care is questioned. Thus, using a qualitative approach, this study aimed to assess the perception people living with the human immunodeficiency virus have in relation to the

occurrence of discriminatory attitudes during dental care.

## METHODS

This qualitative study<sup>(11)</sup> was conducted at the Reference Center for Special Health Care (*Centro de Referência em Atenção Especial à Saúde – Crase*) located in the municipality of Governador Valadares, Minas Gerais, Brazil, from January to July 2019.

Crise is a reference service for PLHIV in the city of Governador Valadares and neighboring municipalities in the eastern region of Minas Gerais. It provides embracement, diagnosis and treatment of PLHIV through a multidisciplinary team<sup>(12)</sup>. Thus, the target audience of this study was PLHIV undergoing treatment at the center as evidenced by the exams attached to medical records. Participants were invited while attending the service after being previously scheduled with the multidisciplinary team.

Inclusion criteria were: being a Crise patient, being treated for HIV, being over 18 years of age, and having sought dental care after diagnosis. Exclusion criteria were: people without a diagnosis confirmed by HIV tests in the medical record, those with communication difficulties, those who did not accept to participate in the study, and those who did not seek dental care after the diagnosis. Two people refused to participate in the study without giving any reasons. Sampling was terminated after saturation<sup>(13)</sup> and the sample comprised 25 participants.

Data were collected through semi-structured interviews<sup>(11)</sup>. This type of interview provides greater freedom and favors elaborating on statements, thereby ensuring better expression. The information was collected in a friendly, comfortable, and reserved environment. The interviews lasted on average 40 minutes and took place after the participants left the dental office.

The semi-structured interviews took place in two stages. The first sought to collect participants' identification data (sex, age, education, and level of education). The second consisted of open-ended questions guided by a script based on a previously published instrument<sup>(14)</sup> and adapted for the present study. These questions were related to the objective of the study, that is, if the patient perceived any discriminatory attitudes for having HIV while receiving care at the dental service.

The interviews were conducted and recorded using the audio recorder of the iPhone 7 Plus. The interviews were later transcribed and submitted to thematic content analysis<sup>(15)</sup>, which took place in three phases. In the 1<sup>st</sup> phase, the pre-analysis or fluctuating reading was performed. This was the first contact with the documents to analyze and get to know the audios, and it was followed by the preparation of the material and the transcripts of the interviews. In the 2<sup>nd</sup> phase, the material was explored and coded. The coding elements, the core meanings, the context elements, and the thematic categories were then extracted. In the third phase, the results were treated in such a way as to be meaningful and valid. The following categories emerged: "Fear of disclosing the diagnosis to the health care professional" and "health care professionals' refusal to provide care".

This study was conducted in accordance with Resolutions 466/2012 and 510/2016 of the National Health Council. It is part of a project approved by the Ethics Committee of the Federal University of Juiz de Fora (Approval No. 1.821.072). Participants who agreed to participate in the study signed an Informed Consent Form. The participants had their names coded as P (patient) and numbered from 1 through 25 according to the order of the interviews. Their personal information has been preserved and only the interviewer had access to them.

## RESULTS AND DISCUSSION

The participants in this study were men and women aged 35-65 years. Only one participant was illiterate. The literate participants' lowest level of education was incomplete primary education, and the highest was complete higher education.

The categories "Fear of disclosing the diagnosis to the health care professional" and "health care professionals' refusal to provide care" are presented below.

### **Fear of disclosing the diagnosis to the health care professional**

This category shows that the fear of disclosing the diagnosis to the health care professional is related to the fact that the participants do not deem necessary to inform that as the facility is a reference center for PLHIV. However, some participants said that they disclosed their diagnosis only to the dentist they trusted:

*“At the time, I disclosed it to only one person, the only dentist of whom I was a patient. I trusted her a lot. I even think that even her assistant didn’t know. But, honestly, today it is difficult to trust these people that are being employed by health centers. It is not because they do not learn professional ethics at school, no, but I believe that today they think everything is normal, everything is natural. But, for those who have it, it is different, I have no prejudice or anything, but I still don’t think it is normal to be talking about it in an environment that is not appropriate.” (P1)*

According to the report described above, the participant felt confident to talk about his serological condition only to the dentist he trusted. This behavior may suggest that, at some point, other professionals did not show confidence. Article 5 of the Dental Ethics Code<sup>(16)</sup> says that professionals must keep confidentiality of the information acquired while performing their duties. Thus, in addition to committing an ethical infraction, professionals who act differently from what is established by the legislation also compromise the relationship of trust between the patient and the professional, sometimes limiting the ideal monitoring of this patient and causing stigmatization.

In the following report, a patient said she has the courage to inform about her diagnosis. Then, she observes extra biosafety actions during dental procedures, as described in the following statement:

*“Whenever I speak, they put on two gloves. But I agree, I think it’s normal.” (P7)*

The excessive biosafety described by the patient can be an indication of discrimination. Although the participant in the present study did not interpret it as a discriminatory act, another study pointed out that the participants interpreted the professional’s excessive protection as discrimination<sup>(17)</sup>.

Another similar report showed that after informing about the diagnosis, care was performed with extra biosafety actions, such as the use of more pairs of gloves by the dental surgeon, which can demonstrate unpreparedness and insecurity to provide care when patients disclose their HIV diagnosis. Thus, it is possible to suggest that despite the advance of knowledge about HIV/AIDS there are seropositive people with little information about what is normal and standard care for any social being.

In other situations, the interviewees in the current study did not disclose their diagnosis in the beginning of the consultation. They only did so during a procedure, and they noticed insecurity on the part of the professionals, who appeared to be scared and unprepared. There was a professional that even changed the conduct with the patient and informed him that he should have reported his health conditions during anamnesis prior to the clinical procedure. That matter is described below:

*“He was more on his own. When I thought about bleeding when it came to removing the tooth, I immediately wanted to tell him, because what if something happened to him? I don’t know, do you?! Then I told him, and then he told me off and said that I should have said it before. He got more fearful then. I said it at the last minute, I think I should have said it earlier.” (P10)*

This behavior of the participant may be associated with the previous experience of prejudice, which may lead him to omit the diagnosis as a defense. It should be noted that a study pointed out that more than half of the participants omitted their serological condition from the dental surgeon in the anamnesis<sup>(17)</sup>, possibly because they share the same thought as P10.

This defense mechanism can compromise the quality of care provided, as the dentist’s lack of knowledge of the patient’s real condition can lead to fragmented and inadequate treatment. On the other hand, it is expected that the professional does not consider the HIV diagnosis as a sign for the patient’s exclusion or the need for additional individual protection measures. In that regard, it is considered ideal that dental surgeons adopt an egalitarian stance, considering all patients as potentially infected and routinely using equal safety measures for all<sup>(18)</sup>.

It should also be noted that the risk of contamination of dental surgeons by HIV is extremely low compared to other diseases<sup>(19)</sup>, and, although the risk of contamination is minimal, these professionals are at increased risk of contamination because they are in contact with fluids, such as blood and saliva, that can contain viruses.

Another point to be highlighted is that some interviewees reported living with the HIV virus even if they did not understand the importance of this information for the health professionals who cared for them:

*“Oh, I am obliged to inform the “dentist”, ain’t I?” (P6)*

Stigma, which is linked to the idea that individuals living with HIV/AIDS come from marginalized homosexual populations who live in sexual promiscuity or use drugs, can negatively influence the availability of health professionals

to provide care<sup>(20)</sup>. In addition to stigmatization, another factor that stands out is the fear of contamination due to little knowledge about HIV transmission in both the medical and dental environments<sup>(21,22)</sup>. It is interesting to note that lower levels of knowledge about HIV/AIDS among different health professionals included in a study were associated with higher levels of stigmatizing attitudes towards PLHIV<sup>(22)</sup>.

The reports presented in the current study are consistent with the literature regarding the evaluation of the attitude of dentistry professionals and students<sup>(23-25)</sup>. One study assessed the attitudes of dental students towards PLHIV and found that 92% of students were reluctant to treat patients and that discrimination was high (87%). Among reluctant students, the majority showed a negative trend in relation to patients<sup>(24)</sup>. Another study carried out in China with students and dental surgeons pointed out that there is little comfort or willingness to care for HIV-positive patients, with only 25% of dental surgeons showing positive attitudes towards PLHIV. These data indicate that it is necessary to disseminate more information, exercises, and group discussions to reduce stigma and improve attitudes<sup>(25,26)</sup> and highlighting that the best conduct to provide dental care is to indiscriminately adopt biosafety procedures as a routine in any service<sup>(27)</sup>.

### Health care professionals' refusal to provide care

This category describes the health care professionals' refusal to provide care identified in the interviewees' reports. It is a form of discrimination that often manifests itself as interrupting the procedure from the moment the patient reveals that he is living with HIV. This fact is evidenced in the following statement:

*"(...) he had the greatest prejudice. When I told him, he just stopped what he was doing. The service started and I told him. At the time, he stopped what he was doing, only then he just put the dressing on, because he was obliged to put it on, in short. He had the greatest prejudice. He just put it on and then agreed to take it off and continue the treatment, but when I came back, he didn't even take it off" (P14)*

There are reports of consultations being postponed countless times without an explanation, and services have even been cancelled:

*"I went to the center several times and they always said the same thing, they put the blame on pressure or something else, but they could never see me. I would book an appointment twenty days in advance and the day came they postponed it to ten days later, I would go back there, and they would not see me. It was always the same excuse." (P3)*

There was also a situation in which the dental surgeon refused the service claiming that the procedure should be done at a private level due to structural issues:

*"When I went back there he said: - No, unfortunately your case is not for me. It has to be performed by a private "dentist". I went to a "dentist" at the primary health care center and he saw me the at the first time I went because he couldn't refuse. I informed him when I was close to other people." (P5)*

There were also situations in which the interviewee reported the diagnosis to a dental surgeon from the public health service, proposed to pay for the treatment and the professional refused the service:

*"The "dentists" in my city don't like to see me. The "dentist" checked everything and didn't want to do anything. Even if I paid the canal treatment twice, she wouldn't want to do it. But not for that, I will sue her, may God take care of her. Not all professionals like to care for people like me." (P22)*

There is a report that shows there was discrimination when the patient decided to inform so he chose not to disclose it anymore:

*"(...) Now, I already say that from now on I no longer tell anyone that I have this problem when I have an appointment because there's this prejudice against me. They have to get by. Put on 7 gloves, 10 gloves." (P8)*

The refusal to provide care after disclosing the serological condition was identified in the participants of the current study. This refusal may reflect discriminatory behavior by the dental surgeon. Interrupting care provision and scheduling, postponing consultations without a coherent explanation, and telling patients that treatment can only be carried out in a private context suggest discrimination. These attitudes increasingly make people hide their serological situation and live with great emotional stress, low self-esteem and feelings of guilt<sup>(28,29)</sup>. It also compromises the

patient's comprehensive treatment. It should be noted that health professionals have an ethical obligation to provide confidential care to everyone, without judging their gender identity, sexual orientation, life choices and behaviors, or health condition<sup>(30)</sup>.

Discriminatory behavior can be the result of deficiencies in the training of professionals, in which there is a focus only on the practical/technical part of dental treatments<sup>(31)</sup> without attention being paid to comprehensive and humanistic treatment. Thus, the training of the dental surgeon must take into account social needs and the teaching-service integration and be in line with national health promotion policies. Humanized and integralist training can be a way to improve the conduct of professionals<sup>(32)</sup>.

In addition to prejudice and fear of contamination, another possible reason pointed out as refusal of care is the fear of losing clients or users of the service because clients will learn that the specific dentist also provides care to PLHIV<sup>(33)</sup>. In the present study, some respondents who were afraid of being refused or receiving differentiated care did not reveal their serological condition. A systematic review pointed out stigma can manifest itself through behaviors and ideologies, such as homophobia, transphobia, racism, and negative opinions about people who inject drugs. These behaviors and opinions can create uncomfortable environments and act as barriers to prevention, treatment and care of HIV<sup>(6)</sup>.

The present study also showed discriminatory attitudes of the dental surgeon when seeing PLHIV, either through refusal of care or excessive biosafety procedures. These findings are in line with the literature<sup>(17,34)</sup>.

Discriminatory attitudes carried out by a health professional can confront the National Public Health Policy (*Política Nacional de Saúde Pública – PNSP*), which aims to improve living conditions and reduce vulnerabilities and health risks arising from social, cultural and environmental determinants<sup>(9)</sup>. It also highlights the need for regulation regarding the embracement and care of PLHIV in both national policies and health care training environments.

The data in the present study indicate that when faced with discriminatory situations patients fail to inform their diagnosis, start to understand the extra measures of biosafety as “normal” or incorporate more suffering into their routine after being refused care, as shown in the participants' reports. Thus, in addition to the need to insert the theme in national policies, there should be encouragement for informative approaches to cover PLHIV and provision of care by dentists.

Health professionals can benefit from training together with PLHIV<sup>(35)</sup>. Educational materials and informational lectures on forms of HIV contamination and transmissibility in health services are essential. Actions that increase the awareness and sensitivity of health professionals can help overcome barriers and stimulate better outcomes in PLHIV. The professional-patient bond must be more humanized and health professionals must act in order to reduce stigma, considering that this can help in the prevention of new HIV infections in addition to increasing the bond and adherence to treatment as a whole<sup>(8)</sup>.

The results of the present study cannot be generalized, considering the methodology used<sup>(36)</sup>. However, the attitude reported by the interviewees is reiterated by the existing literature. In that regard, they can be used to promote the social education of professionals and students in the field of Dentistry and guide other studies related to the theme.

## CONCLUSION

This study indicated that people living with the human immunodeficiency virus are afraid of informing their diagnosis to the dentist and thus omit it. Also, they noticed the presence of discriminatory attitudes by dentists, including the professionals' refusal to provide care and the excessive use of biosafety measures.

The study suggests that there is a need for greater training and awareness of dentists about the transmission, prevention, and treatment of HIV, as well as the humanization of care for people living with the human immunodeficiency virus.

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## CONFLICTS OF INTEREST

The authors declare that there are no conflicts of interest.

## CONTRIBUTIONS

**Sibele Nascimento de Aquino** and **Brisa Ketrine Lustosa de Souza** contributed to the study conception and design, and to the writing/revision of the manuscript. **Ana Virgínia Fonseca Alves** contributed to the acquisition of data and to the writing/revision of the manuscript. **Lucas Eduardo Calheiros, Francielle Silvestre Verner, Waneska Alexandre Alves** contributed to the analysis and interpretation of data and to the revision of the manuscript.

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