

Impacts of health of users with HIV/AIDS in a specialized service

Impactos da saúde bucal de usuários com HIV/Aids em um serviço especializado

Impactos de la salud bucal de usuarios con VIH/SIDA en un servicio especializado

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ABSTRACT

Objective: to understand the perception of users of a Specialized Care Service (SAE- *Serviço de Assistência Especializada*) in HIV/AIDS about their oral health. **Method:** qualitative research that used the techniques of participant observation and focal group. For the analysis of the material produced, categories of analysis, construction of dialogical map and identification of linguistic repertoires were used. **Results:** impacts arising from oral health problems such as: inability to eat properly, feeling ashamed due to tooth loss, inability to perform physical exercises and, as the main barrier to access to dental treatment, fear of exposure to practices of discrimination and prejudice. **Final considerations:** we need the implementation of policies of Permanent Education to all professionals involved in the care for this population, to ensure users' rights, ensure qualified care, and create security and trust relationships with individuals living with HIV/AIDS, in access to services.

Descriptors: Oral Health; HIV Seropositivity; Quality of Life; Qualitative Research; Health Services.

RESUMO

Objetivo: compreender a percepção de usuários de um Serviço de Assistência Especializada em HIV/Aids sobre sua saúde bucal. **Método:** pesquisa qualitativa, com uso das técnicas de observação participante e grupo focal. Para análise do material produzido, utilizaram-se categorias de análise, construção de mapa dialógico e identificação de repertórios linguísticos. **Resultados:** identificaram-se impactos advindos dos problemas de saúde bucal como: não conseguir alimentar-se adequadamente, sentimento de vergonha devido à perda dentária, incapacidade de realizar exercícios físicos e, como principal barreira de acesso ao tratamento odontológico, o receio de exposição a práticas de discriminação e preconceito. **Considerações finais:** necessita-se da implementação de políticas de Educação Permanente a todos os profissionais envolvidos no cuidado a esta população, para atender aos direitos dos usuários, garantir atendimento qualificado e criar relações de segurança e confiança com os indivíduos vivendo com HIV/Aids, no acesso aos serviços.

Descritores: Saúde Bucal; Soropositividade para HIV; Qualidade de Vida; Pesquisa Qualitativa; Serviços de Saúde.

RESUMEN

Objetivo: comprender la percepción de los usuarios de un Servicio de Asistencia Especializada en VIH/SIDA sobre su salud bucal. **Método:** investigación cualitativa, con uso de las técnicas de observación participante y grupo focal. Para el análisis del material producido, se utilizaron categorías de análisis, construcción de mapa dialógico e identificación de repertorios lingüísticos. **Resultados:** se identificaron impactos provenientes de los problemas de salud bucal como: no puede alimentarse adecuadamente, sentimiento de vergüenza debido a la pérdida dental, incapacidad de realizar ejercicios físicos y, como principal barrera de acceso al tratamiento odontológico, el temor de exposición a prácticas de discriminación y prejuicio. **Consideraciones finales:** se necesita de la implementación de políticas de Educación Permanente a todos los profesionales involucrados en el cuidado a esta población, para atender a los derechos de los usuarios, garantizar atención calificada y crear relaciones de seguridad y confianza con los individuos viviendo con VIH/SIDA, en el acceso a los derechos mantenimiento.

Descriptorios: Salud Bucal; Seropositividad para VIH; Calidad de Vida; Investigación Cualitativa; Servicios de Salud.

INTRODUCTION

AIDS remains a serious health condition. In Latin America and the Caribbean, despite the downward trend in the number of new HIV infections, approximately 120,000 new cases are diagnosed each year⁽¹⁾. In Brazil, many investments have been made to transform into universal access to specialized services, diagnosis and treatment, demonstrating that it is possible for the state to pay adequate attention to those who need it⁽²⁾. With the increase in the life expectancy of people living with HIV/AIDS, it becomes relevant to study the potential obstacles they face in order to maintain their quality of life⁽³⁾. However, it should be considered that health and quality of life are multidimensional concepts that can include both objective measures of disease severity, as well as the individuals' perception of their autonomy and subjectivity⁽⁴⁻⁵⁾. There is a consensus that oral problems impact on quality of life and that, therefore, the relationship between oral health and quality of life is determined by a variety of conditions that involve the individual's perception, values and limitations found in performing daily activities⁽⁶⁻¹⁰⁾.

The World Health Organization defines quality of life as:

individual perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is, of course, determined by physical health, psychological state, level of independence, social relationships, environmental factors and personal beliefs (p.354)⁽¹¹⁾.

Many instruments have been used to assess the impact of oral health on quality of life. Of these, the Oral Health Impact Profile (OHIP) questionnaire, in its reduced version OHIP-14 was created with the purpose of assimilating the quality of life related to oral health and used in several studies in dentistry^(7,8,12-14). In order to know the impact of oral problems on the quality of life of HIV/AIDS patients, from the field of quantitative methods, it is commonly sought to establish cause and effect relationships with the use of instruments such as OHIP- 14, which mainly measure the negative impacts⁽⁷⁻⁹⁾. Nonetheless, evidence from the social sciences shows that this type of approach does not allow for a deepening of the variety of feelings generated by the subjects, also requiring qualitative studies to investigate the quality of life in the various aspects of living with HIV/AIDS, including also the positive aspects^(3,15-20).

In this way, it was problematized how people living with HIV/AIDS understand the impacts of oral health in their life. These people are presumed to relate HIV/AIDS infection to impacts related to their oral health, which interfere with their quality of life. The qualitative approach adopted in this study differentiates itself by prioritizing the speech of people with HIV/AIDS, which makes it possible to make individuals' perceptions of the impact of oral health on their social relations, autonomy in the performance of daily activities and the means of coping with this condition of life.

OBJECTIVE

To understand the perception of users of a Specialized Care Service (SAE- *Serviço de Assistência Especializada*) in HIV/AIDS about their oral health.

METHOD

Ethical aspects

This research was approved by the Research Ethics Committee of the *Centro Universitário CESMAC*, recognized by the National Commission for Ethics in Research, the National Health Board (CONEP-NHB) and complies with the guidelines and standards set forth in NHB Resolution 466/2012. All participants signed the Free and Informed Consent Term and, to protect their anonymity, their names were replaced by alphanumeric codes.

Theoretical-methodological framework and type of study

This research used a qualitative methodology, using the techniques of Participant Observation and the Focus Group, and the analytical framework of Discursive Practices⁽²¹⁻²²⁾.

Methodological procedures

Study setting

The research was conducted by a Specialized Care Service in HIV/AIDS located in a capital in the Northeast region of the country. This service is intended for people living with HIV/AIDS and offers: guidance and psychological support, consultations in infectology, gynecology, pediatrics and dentistry; control and distribution of antiretrovirals; conducting monitoring exams; distribution of prevention inputs; educational activities for treatment compliance and for prevention and control of sexually transmitted infections and AIDS. In addition to the assistance practices, being characterized as a school service, this SAE incorporates in its daily practices of research, teaching and university extension.

Data source

Non-probabilistic sampling was used for convenience, and it was used as a criterion to participate in the study: to be a user of a Specialized Care Service and to be diagnosed with HIV/AIDS. It was identified that the days with the highest flow of users in this service were those who had medical care with scheduled demand. In general, this user, who was previously scheduled for medical care, was in full shift (morning or afternoon) in the SAE and, thus, associated the consultation with other activities, such as participation in health groups. Thus, for two weeks, being two days in each of those weeks - the days with scheduled demand for the medical professional -, the users who waited in the waiting room for the medical attention were invited to participate in a focus group for research purposes, being communicated to them the date and time that were previously defined. On the day established for the focus group, the users, while waiting in the waiting room of the SAE, were again invited to participate in the research. 10 users accepted to participate and presented on the date and time of the focus group, being: 4 women and 6 men, aged between 40 and 66 years. Regarding the time of infection, 7 participants were more than 10 years old, 4 of them over 20 years old. Only 3 users had up to 2 years of infection. To ensure the adequate number of participants, in this study, data saturation was also considered.

Data collection

Participant observation included periodic visits by the main investigator to SAE between June 2015 and July 2016. The visits allowed the main investigator to perform: conversations with health professionals about the work processes and assistance in SAE; dialogues with users and family members while waiting for service on the use of the service and the care offered to them; in addition to participating in some on-site health groups that were offered to users. This made it possible to get to know the daily life of the service and the provision of care for users, involvement with people living with HIV/AIDS assisted in the SAE as well as with health professionals, and contact with the values shared among these subjects⁽²²⁾. After each visit, the experiences were recorded in a field diary. This period favored the approach of the researcher with the field, allowed to pool different reflexivities and assisted in the choice of the technique for producing the information. Notes made during this process served to subsidize the analysis procedures.

For the production of information, the focal group technique was used, because it is a space that privileges the dialogue, allows sharing experiences and coproducing meanings⁽²²⁾. The group was coordinated by two researchers; took place in July of 2016, with an approximate duration of 100 minutes, recorded in audio and guided by a script created from the inspiration in themes about quality of life present in the OHIP-14. The themes were adapted to pictures depicting the following scenes: feeling ashamed; shame of laughing at pubic; withdrawal from social life; insomnia; pain when eating food; mouth pains; difficulty speaking some words; limitation of physical capacity; limitation for chores; concern and sadness; and taste of the food. Figures were used to make conversations and the conduction of the focal group easier.

The size of the group, with 10 participants, allowed the coordinators the conduction process, favoring the speech of all participants and ensuring the registrations⁽²²⁾. Although the focus of the conversations in the group was on oral health and its implications on quality of life, the coordinators remained attentive to other issues that arose during the discussion. This flexibility allowed the dialogue of several themes inherent in the daily life of living with HIV/AIDS.

Organization and analysis of data

The audios recorded during the focus group were fully transcribed, a strategy that allows to identify the distribution and the frequency of the speech between the interlocutors⁽²²⁾. During this process, names of participants were replaced, using the coding from P1 to P10. After this step, the statements were categorized through the construction of the Dialogical Map, a feature that allows to give visibility to the analysis process in the construction of the research by exposing the context of coproduction of the discursive practices⁽²²⁾. Three thematic categories of analysis were used to reveal the positioning of the speech emitter, exposing the different interactions that can originate⁽²²⁾: a) oral health-disease process and relation with HIV infection; b) access to dental treatment; and c) relationship between oral health and quality of life.

Afterwards, we set out to identify the linguistic repertoires that compose the discursive practices. Analyzing them allows us to perceive how senses were produced on a certain subject⁽²²⁾. Meaning production is understood as a social practice, of a dialogical character, constructed through the language in use⁽²¹⁻²²⁾. From the identification of linguistic repertoires, the categories initially produced were adjusted to three themes of analysis: the oral health-disease process related to HIV infection; barriers to access dental treatment; and oral functions impaired by HIV/AIDS.

Chart 1 – Dialogical Map fragment with speeches of participants in the focal group, Maceió City, Alagoas State, Brazil, June 2016

Parti-cipant	Oral health-disease process related to HIV/AIDS infection	Access to dental treatment	Relationship between oral health and quality of life
P5	Occasionally, it infects (gingiva) because of the prosthesis, but also, the medicine also causes this to occur, right? I've lost almost everything and I'm here.		
P4			And I, after I started taking the medications, it seems that I only live sucking lemon, that the mouth only lives bitter (laughs) Yeah, the mouth is bitter, right ... I already use dentures, right? And the few that I have, it seems that everything is numb, got it?
P4		Then I've come, I've been with the doctor several times, it's been five or six months, she cleaned up, right? She told me to extract the rest...	
P4			... it is always frozen and that bitter in my mouth, it seems like nothing I eat, I feel like after the medication. I think it was more the habit of having changed the food, right? Because I used to eat everything before but now...
[...]			

RESULTS

Oral health-disease process related with HIV/AIDS infection

Participants reported that the problems occurred in the mouth had importance in the health-disease process of HIV/AIDS, because they caused impacts on their daily lives. When the issue of tooth or mouth pain was brought to the group, the report was heard:

[...] well, I have no pain, but my oral question is more because of bruxism, because of an emotional issue [...] by their own social pressures, by the family pressures [pause] caused after AIDS. [...] they mess with our emotional [...] interfered with the oral problem, I could not even open my mouth. (P8)

Bruxism is characterized by the act of grinding or clenching the teeth; is a nonfunctional habit of the masticatory system that may be associated with dental or psychological factors.

Participants reported dental loss attributed to medication use, with a consequent physical impact. In this report, there was a feeling of discouragement with the oral condition. Other participants linked medications to problems in the mouth:

Occasionally, it infects [gingiva] because of the prosthesis, but also, the medication also causes this to occur, right? [...] I have almost lost everything [...]. (P5)

[...] I'm very cautious, but when I go [to the dentist], I always have tooth decay and I believe it's because of the medication itself. (P7)

I think my teeth are like this because of the medication; it's very strong and very bitter [...]. (P3)

Periodontal problems are common in the Brazilian population. Once installed, periodontal diseases lead to dental mobility, culminating in the loss of the dental element:

[...] you get your teeth, especially the last ones, the molars [pause], soft [...] I've lost my back and bottom teeth. It is just that, it is [pause] as if it was loose [laughter] or something; you would pick up the tooth and feel. (P8)

Injuries to the oral mucosa as a complication of HIV infection are a common event during the natural history of the disease. Although these injuries have decreased considerably with the advent of antiretroviral therapy, it is noted in the present study that they are still present in the history of the individuals surveyed:

[...] I had several oral infections, [...] it is not easy [...] sometimes, I'm having it now, [...] I think something must be happening with CD4 because it dropped from seven hundred to four hundred, right? So something is happening [...] this is what impacts me most nowadays; it's these crises that I'm having [...] I could not swallow because I had too much pain. (P8)

The term CD4 used by participant refers to the CD4 + T lymphocytes that are the body's defense cells and the main targets of the HIV virus. The involvement of the oral mucosa in seropositive individuals is present from the beginning of the disease and

there is an understanding among the study participants that this occurrence is related to the infection:

It is the same problem of her as well, the infection, the cold sore. Sometimes it comes out in the mouth, sometimes it comes out in the throat, I cannot swallow anything, it burns, sometimes it comes out on the tongue, when it comes out on the tip of the tongue, I cannot eat anything at all [...]. (P2)

It is not candid, is it? When immunity is low, the person tends to have a lot of candida. (P8)

Some difficulties reported by participants due to HIV/AIDS and the sufferings that appear in the mouth, show limitations and incapacities to perform physical exercises:

I cannot walk. When I step on it, it's as if I'm going to move it here [takes the jaw]. Now it got better, after I started doing the exercise [...] it was like it was going to leave [...] when I took a step, it seemed that I was going to leave the place, imagine if I run, right? Because when you're running it messes with everything, right? (P9)

Within the health-disease process, the emotional aspects should be highlighted, which may contribute to the evaluation of the quality of life. When asked in the group if someone had already felt ashamed when smiling or talking about problems with their mouth or teeth, the story was heard:

I spent more than 20 years just being a waitress, then, I smiled a lot, I played a lot, I let out a lot of joke, but I do not do it anymore, when I do it, it seems like crying is coming [...] I feel ashamed of opening my mouth [...] I want to talk to the doctor, I want to smile, I want to die smiling, I was a waitress for what? Was it not to bring joy to the people? (P4)

[...] the oral question in the case of people living with HIV/AIDS is horrible, it generates an anxiety that you have some oral problem [...] it messes with you from all forms of pain and you say, "What now? How am I going to extract that tooth" [...] the desire is to have your teeth all taken out right away. (P8)

According to the participants' speeches, anguishes and conflicts seem to be parallel to the HIV/AIDS illness, making themselves present in the emotional and social aspects of the daily life of these people.

Barriers to access to dental treatment

Access to dental services is important preventive and curative support to all individuals, especially those with systemic diseases that are determinant for oral complications. Study participants reported that trust and the bond with the professional dentist, such as the recognition of the importance of caring for teeth, predispose the search for dental care:

I love dentists too, I love dentists! Then, when I go to the dentist, I settle down and straighten my tooth, because it's good for us to smile, even though! But it's very good, our laughter is our postcard. (P7)

However, for other participants, going to the dentist is a last resort to resolve dental problems, which commonly occurs

because of pain or tooth decay. For people living with HIV/AIDS, this means increasing the risk of dental loss:

Then I've come, I've been with the doctor several times, it's been five or six months, she cleaned up, right? She told me to extract the rest. (P4)

And I have already lost all my teeth, I only have four. (P5)

And I have none. (P3)

For participants, the fear of dentist and the fear of transmitting the virus to other people may represent barriers to treatment compliance:

And sometimes fear makes us delay, and then when you get there you have no way out, you have to take it, right? (P7)

[...] I still went to [SESI dental care]. When I got there, [...] I looked at that room, I said "here, right, my place, no, I'm going back to the doctor" [from the HIV service]. [...] And also, right, of not being able to come and tell him [dentist] and use that material on other people. (P4)

In the context of the speech of P4, anguish related to the discomfort and the insecurity in the search for dental care outside the specialized service is noticed, because, at the time, he reported ambiguity of feelings, wishing both to communicate to the dentist his condition of being infected by HIV/AIDS, as well as hiding the disease. He associated his concern with the secrecy regarding his condition of bearer, for fear of exposure to situations of prejudice. Participants reported the occurrence of discrimination in the care for people with HIV/AIDS by health professionals:

My dentist had been treating me for 14 years and I had to tell her [that I was HIV-positive]. She already suspected, because a dentist, by mouth, she starts to see, so I decided to tell her. She said, "No, that's ok". [...] Then I felt she was avoiding to schedule the appointment. I said, "Do the following, since you're having some difficulty, check me to be the last customer. She said, "I will not serve you because if I go to you, I'll lose all my clients". (P8)

The speech of P8 reveals, both on the part of the professional, the violation of the code of ethics, punishable by refusal to meet, as well as negative feelings generated in the individual after having their rights denied, especially when this refusal occurs due to the condition of seropositivity. The reported experience revealed an agonizing episode:

[...] I had a hard time finding another dentist. [...] First, you start to be afraid to say, so I made an immense pilgrimage, I went to one and then to another. [...] I have a story that the dentist broke his device when I told him [...] and said he was not going to answer me because it was not his case, and that's a recent one. They have many stories; every one brings their luggage, their history. [...] So it is these realities that we encounter, found in the past, in the 90s and still find today. (P8)

In participant observation and in reports during the focus group, it was possible to perceive the great effort to keep the diagnosis of HIV/AIDS confidential, as well as the fear of being discovered and having to make use of strategies to maintain this secret.

Oral functions hampered by HIV/AIDS

The individual affected by HIV/AIDS begins to face various transformations in their lives that result, as a rule, in social deprivation, affecting daily activities that are pleasurable and essential to the well-being of the people. In relation to this, some participants reported important dietary limitations due to oral-dental deficiencies:

[...] the tooth becomes soft; it is [pause] because of the feeding. Yeah, you're going to chew and cannot chew anything hard, I'm practically eating slimy food, you know? It's difficult, it's complicated. (P9)

That's why I'm eating slimy food. [...] When I eat anything solid, it bleeds and it bleeds a lot. [...] That limits, there I am no longer chewing almost anything, like slimy even more. To not go through the blender, I have to put in the pressure cooker to be very soft, [...] not even an apple I can eat; I have to put in the blender [laughs]. (P9)

When treated in the group the issue of altered taste, once again, HIV medications appeared to cause uncomfortable events, taking pleasure in eating and impacting their quality of life:

And I, after I started taking the medications, it seems that I only live sucking lemon, that the mouth only lives bitter [laughs] [...] it seems like everything is numb, you know? It is always frozen and with that bitter in my mouth, it seems that nothing that I eat makes me taste after the medication. (P4)

The point is that I feel dry mouth and I do not know if it's because of the medication. (P2)

I don't feel like eating. (P4)

Exposure to chemical substances is one of the most common causes of taste loss and among medications with this side effect are protease inhibitors - HIV treatment. The mouth has a wide representation of senses and the palate is an important body sense that allows us to recognize the flavors. However, bitterness and dry mouth sensation reported here, may not mean a side effect of medications, but a strong relationship with the emotional component of all illness:

[...] and this issue of girls having a bitter mouth sometimes does not even need to be because of the medication [...] but a good hygiene that we did not do or dawned head down, then we'll eat something and it's tasteless, right? (P7)

In participant observation, it was identified that during the dental care to SAE users, educational-preventive information on oral health care. It was also observed that the work routine in this service includes lectures, round conversations and group dynamics, as a way to keep patients well informed about mouth care.

[...] and then I use the dental floss [...] I always try to go round in conversation. Hygiene is fundamental, got it? It's either in the health problem with the medication we take, yes or no, we use floss that most of the time, we do not use! (P7)

I brush my teeth about four times a night. Because of diabetes, I get up enough to eat, it's eating, brushing! Eating, brushing! (P6)

It's very important to bring over this theme to us, right? [...] it is because it really is very important to talk about our oral health because it is through mouth that we take our medications, we drink water, we breathe. (P7)

It was observed that participants who showed greater compliance with the dental discourse deserve greater care with the mouth, and those who had more events of oral-dental deficits, when talking about their experiences, encouraged others to make their reports, contributing to the enrichment of the group discussion.

DISCUSSION

As found in the literature, study participants stated that there is a need for adaptations in living with HIV/AIDS. They talked a lot about their diet, reporting the changes they experience in eating habits, which is also found in other studies^(18,23). Healthy food, understood as a human right, must include biological, social and cultural needs⁽²⁴⁾. However, some participants said that due to the disease, they present oral health problems and, therefore, they need to limit themselves to the consumption of processed foods, which lose their taste and compromise adequate nutrition. In addition, the alimentary practice constitutes a social function, since it acquires diverse meanings and changes to each historical period and context⁽²⁵⁾. Thus, the negative impact on the quality of life of people living with HIV/AIDS is also present when they find it embarrassing to participate in meetings, social gatherings and social events, moments in which due to oral problems, it is not possible to share with friends and family.

Participants also reported limiting routine work functions due to physical weakness and fatigue, similar to previous study⁽¹⁸⁾. Feeling physically limited certainly involves feelings of inadequacy and lack of autonomy, with consequent harm to the subject. In fact, adequate and supervised physical activity can contribute to the psychological well-being and enhancement of the immunity of people with HIV/AIDS⁽²⁶⁾.

A key issue for people living with HIV/AIDS is medication compliance. Although these people understand the importance of treatment, factors such as side effects often lead to withdrawal of medication⁽²⁷⁾. This was evidenced in this study, through the speeches, which associated unpleasant sensations occurred in the mouth to the treatment, even taking away the pleasure of eating. Although the research participants are informed about the possible effects of the medications in the body, there is still a need to better orient their relationship with tooth loss and other complaints of discomfort in the oral cavity.

Studies conducted with HIV-infected and non-HIV-infected individuals show that injuries on the oral mucosa interfere negatively with quality of life^(12,28). Periodontal problems may be potentiated by HIV infection, and its susceptibility is conditioned by low immunity⁽²⁹⁾. They affect the tissues of tooth support and are also influenced by problems related to oral hygiene, even when information about such care is insufficient during the course of individuals' lives⁽³⁰⁾. These diseases may be potentially disabling and capable of influencing people's daily lives⁽²⁸⁾. These problems were pointed out in several statements by participants, impacting their quality of life.

A previous study, which evaluated the impact of tooth loss on quality of life, highlighted the issue of the subject feeling ashamed, stating that the aesthetic function of the teeth is often considered more important than the masticatory function⁽¹⁹⁾. However, this feeling may vary from person to person, because it is a subjective issue of a psychological, social and cultural nature⁽¹⁴⁾.

The quality of life of these people is also impacted by the anguishes experienced and the stigma related to HIV/AIDS⁽⁴⁾. To speak of prejudice with people living with HIV/AIDS is to talk about a phenomenon that generates much suffering⁽¹⁵⁾. It is verified that, among the situations to be faced daily by people with HIV/AIDS, are the episodes of discrimination and rupture of affective relations⁽¹⁶⁾. Prejudice produced in the family environment are reported as the greatest difficulty experienced by people with HIV/AIDS⁽³⁾. Religiosity and family support were considered support pillars in coping with the disease, as was also found in another study⁽¹⁶⁾.

Prejudice to HIV/AIDS is built on socio-cultural concepts prior to illness, such as stigmata in relation to sexuality and gender, closing a set of standards or stereotypes that lead to the punishment of those who surpass them, who become victims of prosecution, isolation and rejection⁽³¹⁾. Since the discovery of the virus, attitudes of stigmatization of the disease constitute social barriers to people with HIV/AIDS⁽³²⁾. When discrimination is practiced by professionals in the health services, as reported by some study participants, a strong barrier of access to oral health and, consequently, to quality of life⁽³³⁾. Well-informed professionals on HIV-related technical issues, with participation in Permanent Education to care for HIV-positive people and with a history of previous professional experience with these users, are more willing to serve this population⁽³⁴⁾. Permanent Education in health, when present in the services, operates changes in the work processes, favors the creation of bonds between the subjects and amplifies the potential of reflection and action on the health needs⁽³⁵⁾, being a fundamental device for the qualification of professionals who care for people living with HIV/AIDS.

Study participants also reported that they avoid seeking dental services in non-specific places for the public with HIV/AIDS, for fear of not having the necessary care to sterilize the equipment and thus be able to transmit the virus. This demonstrates the need for communication to the population about effective measures to control the transmission of this infection, which should be adopted in dental offices⁽³⁶⁾. There is a high probability that participants in the present study were able to access dental services on a regular basis, only from their insertion in the specialized service for HIV/AIDS, when they did not present a good oral condition, a fact similar to that demonstrated in another research⁽¹⁷⁾. It also contributes to the late access to dental services, the ideology of the search for these professionals only when there is risk of injury to the tooth, caries or injury⁽³⁷⁾.

Oral problems perceived by the group studied demonstrated the need to keep people with HIV/AIDS well informed about oral health care. Positive and significantly associated factors with visits to the dentist can lead to high levels of knowledge and perceptions about the importance of oral health for HIV-positive individuals⁽³⁸⁾. The subjective involvement of the dental professional with the production of comprehensive care should be prioritized, building relationships and links with the daily life of users⁽³⁷⁾. There is also a need for care actions that denature dental loss and, thus, positively impact oral health and quality of life

of users⁽⁷⁾. Access to quality dental services in the public health network reduces health inequalities and has a positive impact on the quality of life of the assisted users⁽⁶⁾. It is also demonstrated that the existence of a dental service, in the places of specialized care for people with HIV/AIDS, improves the demand for care, becoming the service preferentially chosen by these users, for the ease of access and guarantee of confidentiality⁽¹⁷⁾.

Study limitations

The dialogue about the topic with users, in the service where they receive assistance, may have been a limitation. However, care was taken not to involve SAE health professionals in the focus group. Researchers were not part of the service and participants were not, on the day of the group, scheduled for dental consultation.

Contributions to the health area

The reports in the study group dealt with domains of the construct quality of life related to seropositivity that extrapolated the proposed theme. The term *prejudice* has permeated every dialogue, and its strong point in denial of care by the dental surgeon. This demonstrates the need to offer dental services in SAE for the care for people living with HIV/AIDS and the implementation of public policies of Permanent Education for all professionals involved in the care for this population. This is yet another study that exposes the importance of an expanded view of care, valuing aspects of a subjective nature that allow the individual to understand in all its dimensions.

FINAL CONSIDERATIONS

The health-disease process involves many aspects of the lives of people with HIV/AIDS. In this study, participants reported

that the impacts of oral health on their lives show limitations for the performance of work and physical activities, and also the aesthetic ones, because they produce damages in the scope of social relations. They also reported not being able to eat properly, have feelings of shame due to tooth loss and feel anguish about the need for dental care. Participants reported that most of the oral problems were the effects of using medications for HIV/AIDS treatment.

Discrimination and prejudice are an important barrier to access to dental services, both for fear of breach of confidentiality and for the discriminatory attitude of the oral health professional. Participants expressed feeling more comfortable in seeking dental services in Specialized Care Services for HIV/AIDS, which demonstrates the current importance of maintaining these services for this population. The creation of spaces for health professionals to discuss practices of prejudice and discrimination against HIV/AIDS and the rights of users in the Brazilian Unified Health System (*Sistema Único de Saúde*) can contribute to a change in the modes of care for these users.

It is considered necessary the implementation of policies of Permanent Education in health to all professionals involved in the care for this population, with the purpose of guaranteeing the qualification of care and offering a greater sense of security and confidence to individuals living with HIV/AIDS in access to services. It is also suggested that the dental surgeon invest permanently in the understanding of what it means for individuals to live with HIV/AIDS. And, from this, to appropriate the multiple senses and social uses of the mouth for these subjects, in order to promote a comprehensive and effective care for their quality of life.

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REFERENCES

1. Pan American Health Organization (PAHO). Joint United Nations Programme on HIV/AIDS (UNAIDS). HIV Prevention in the Spotlight: An Analysis from the Perspective of the Health Sector in Latin America and the Caribbean, 2017 [Internet]. Washington: PAHO, UNAIDS; 2017 [cited 2018 Apr 30]. Available from: <https://unaids.org.br/wp-content/uploads/2018/01/9789275119792-eng.pdf>
2. Greco DB. Thirty years of confronting the AIDS epidemic in Brazil, 1985-2015. *Ciênc Saúde Coletiva*. 2016; 21(5):1553-64. doi: 10.1590/1413-81232015215.04402016
3. Jesus GJ, Oliveira LB, Caliarí JS, Queiroz AAFL, Gir E, Reis RK. Difficulties of living with HIV/AIDS: obstacles to quality of life. *Acta Paul Enferm*. 2017;30(3):301-7. doi: 10.1590/1982-0194201700046
4. Caliarí JS, Reinato LAF, Pio DPM, Lopes LP, Reis RK, Gir E. Quality of life of elderly people living with HIV/AIDS in outpatient follow-up. *Rev Bras Enferm* [Internet]. 2018;71(Suppl 1):513-522. doi: 10.1590/0034-7167-2017-0127
5. Silva J, Saldanha AAW, Azevedo RLW. Variáveis de impacto na qualidade de vida de pessoas acima de 50 anos HIV+. *Psicol Reflex Crít*. 2010;23(1):56-63. doi: 10.1590/S0102-79722010000100008
6. Bulgareli JV, Faria ET, Cortellazzi KL, Guerra LM, Meneghim MC, Ambrosano GMB, et al. Factors influencing the impact of oral health on the daily activities of adolescents, adults and older adults. *Rev Saúde Pública*. 2018;52:44. doi: 10.11606/S1518-8787.2018052000042
7. Oliveira EJP, Rocha VFB, Nogueira DA, Pereira AA. Quality of life and oral health among hypertensive and diabetic people in a Brazilian Southeastern city. *Ciênc Saúde Coletiva*. 2018;23(3):763-72. doi: 10.1590/1413-81232018233.00752016
8. Díaz-Reissner CV, Casas-García I, Roldán-Merino J. Calidad de vida relacionada con salud oral: impacto de diversas situaciones clínicas odontológicas y factores socio-demográficos. revisión de la literatura. *Int J Odontostomat*. 2017; 11(1):31-9. doi: 10.4067/S0718-381X2017000100005

9. Díaz-Cárdenas S, Meisser-Vidal MA, Tirado-Amador LR, Fortich-Mesa N, Tapias-Torrado L, González-Martínez FD. Impacto de salud oral sobre calidad de vida en adultos jóvenes de clínicas odontológicas universitarias. *Int J Odontostomat*. 2017;11(1):5-11. doi: 10.4067/S0718-381X2017000100001
10. Guerra MJC, Greco RM, Leite ICG, Ferreira EF, Paula MVQ. Impact of oral health conditions on the quality of life of workers. *Ciênc Saúde Coletiva*. 2014; 19(12):4777-86. doi: 10.1590/1413-812320141912.21352013
11. The WHOQOL Group. What quality of life? *World Health Forum* [Internet]. 1996 [cited 2018 Apr 30];17(4):354-6. Available from: https://apps.who.int/iris/bitstream/handle/10665/54358/WHF_1996_17%284%29_p354-356.pdf?sequence=1&isAllowed=y
12. Silva CAB, Grado LJ, Fabro SML, Mello ALSF. Oral health related to quality of life in patients with stomatological diseases. *Stomatologija* [Internet]. 2015 [cited 2016 Nov 30]; 17(2):48-53. Available from: <http://www.sbdmj.com/152/152-03.html>
13. Gabardo MCL, Moysés ST, Moysés SJ. Auto percepção de saúde bucal conforme o Perfil de Impacto da Saúde Bucal (OHIP) e fatores associados: revisão sistemática. *Rev Panam Salud Publica* [Internet]. 2013 [cited 2017 Feb 12];33(6):439-45. Available from: <https://www.scielosp.org/pdf/rpsp/2013.v33n6/439-445>
14. Alvarenga FAS, Henriques C, Takatsui F, Montandon AAB, Telarolli Jr R, Monteiro ALCC, et al. Impacto da saúde bucal na qualidade de vida de pacientes maiores de 50 anos de duas instituições públicas do município de Araraquara-SP, Brasil. *Rev Odontol UNESP* [Internet]. 2011 [cited 2016 Nov 11];40(3):118-24. Available from: <http://hdl.handle.net/11449/125978>
15. Costa TL, Oliveira DC, Gomes AMT, Formozo GA. Quality of life and people living with AIDS: relationship with sociodemographic and health aspects. *Rev Latino-Am Enfermagem*. 2014; 22(4):582-90. doi: <http://dx.doi.org/10.1590/0104-1169.3350.2455>.
16. Hipólito RL, Oliveira DC, Gomes AMT, Costa TL. Social representations of quality of life in HIV/AIDS: the role of time since diagnosis. *Rev Enferm UERJ*. 2014;22(6):753-9. doi: 10.12957/reuerj.2014.12840
17. Soares GB, Garbin CAS, Rovida TAS, Garbin AJL. Oral health associated with quality of life of people living with HIV/AIDS in Brazil. *Health Qual Life Outcomes*. 2014;12(28):1-9. doi: 10.1186/1477-7525-12-28
18. Meirelles BHS, Silva DMGV, Vieira FMA, Souza SS, Coelho IZ, Batista R. Percepções da qualidade de vida de pessoas com HIV/AIDS. *Rev Rene* [Internet]. 2010[cited 2016 Nov 11];11(3):68-76. Available from: <http://www.periodicos.ufc.br/rene/article/view/4584>
19. Silva MES, Villaça EL, Magalhães CS, Ferreira EF. Impacto da perda dentária na qualidade de vida. *Ciênc Saúde Coletiva*. 2010;15(3):841-50. doi: 10.1590/S1413-81232010000300027
20. Vargas AMD, Paixão HH. Perda dentária e seu significado na Qualidade de Vida de adultos usuários de serviço público de saúde bucal do Centro de Saúde Boa Vista, em Belo Horizonte. *Ciênc Saúde Coletiva*. 2005;10(4):1015-24. doi: 10.1590/S1413-81232005000400024
21. Spink MJP, Menegon VM. A Pesquisa como prática discursiva: superando os horrores metodológicos. In: Spink MJP, organizadora. *Práticas discursivas e produção de sentidos no cotidiano* [Internet]. Rio de Janeiro: Centro Edelstein de Pesquisas Sociais; 2013. p. 42-70 [cited 2017 Feb 12]. Available from: http://www.bvce.org.br/DownloadArquivo.asp?Arquivo=SPINK_Praticas_discursivas_e_producao_FINAL_CAPA_NOVAc.pdf
22. Spink MJP, Brigagão JIM, Nascimento VLV, Cordeiro MP, organizadoras. A produção de informação na pesquisa social: compartilhando ferramentas [Internet]. Rio de Janeiro: Centro Edelstein de Pesquisas Sociais; 2014 [cited 2017 Feb 12]. Available from: http://www.bvce.org.br/DownloadArquivo.asp?Arquivo=SPINK_A_producao_de_informacao.pdf
23. Pinto ACS, Fiuza MLT, Pinheiro PNC, Vieira NFC, Galvão MTG. Experiencias de portadores de HIV/AIDS sobre la perspectiva de la promoción de la salud. *Online Braz J Nurs*. 2012;11(3):815-28. doi: 10.5935/1676-4285.20120054
24. Ministério da Saúde (BR). Secretaria de Atenção à Saúde. Departamento de Atenção Básica. PNAN: Política Nacional de Alimentação e Nutrição [Internet]. Brasília; 2013 [cited 2017 Feb 12]. Available from: http://bvsms.saude.gov.br/bvs/publicacoes/politica_nacional_alimentacao_nutricao.pdf
25. Moreira SA. Alimentação e comensalidade: aspectos históricos e antropológicos. *Cienc Cult* [Internet]. 2010 [cited 2018 May 6];62(4):23-6. Available from: <http://cienciaecultura.bvs.br/pdf/cic/v62n4/a09v62n4.pdf>
26. Gomes RD, Borges JP, Lima DB, Farinatti PTV. Effects of physical exercise in the perception of life satisfaction and immunological function in HIV-infected patients: Non-randomized clinical trial. *Rev Bras Fisioter*. 2010;14(5):390-5. doi: 10.1590/S1413-35552010000500007
27. Gomes AMT, Silva EMP, Oliveira DC. Social representations of Aids and their quotidian interfaces for people living with HIV. *Rev Latino-Am Enfermagem*. 2011;19(3):485-92. doi: 10.1590/S0104-11692011000300006
28. Liu LJ, Xiao W, He QB, Jiang WW. Generic and oral quality of life is affected by oral mucosal diseases. *BMC Oral Health*. 2012;12:2. doi: 10.1186/1472-6831-12-2
29. Vieira TR, Peret ACA, Peret Filho LA. Alterações periodontais associadas às doenças sistêmicas em crianças e adolescentes. *Rev Paul Pediatr*. 2010;28(2):237-43. doi: 10.1590/S0103-05822010000200017
30. Broadbent JM, Zeng J, Foster Page LA, Baker SR, Ramrakha S, Thomson WM. Oral health-related beliefs, behaviors, and outcomes through the life course. *J Dent Res*. 2016;95(7):808-13. doi: 10.1177/0022034516634663
31. Silva LC, Felício EEAA, Cassette JB, Soares LA, Morais RA, Prado TS, et al. Psychosocial impact of HIV/AIDS diagnosis on elderly persons receiving care from a public healthcare service. *Rev Bras Geriatr Gerontol*. 2015;18(4):821-33. doi: 10.1590/1809-9823.2015.14156
32. Anjos ACF, Vilela ABA, Oliveira DC. Produção do cuidado interdisciplinar em pessoas soropositivas: um estudo de representações sociais. *J Health Biol Sci*. 2014;2(4):202-7. doi: 10.12662/2317-3076jhbs.v2i4.74.p202-207.2014

33. Lelis RT, Garbin CAS, Garbin AJI, Soares GB. Vivendo com HIV/AIDS: estudo da ocorrência de discriminação nos serviços de saúde. *Rev Bras Pesq Saúde*. 2012;14(4):22-8. doi: 10.21722/rbps.v14i4.5114
 34. Maia LA, Vieira-Meyer APGF, Nuto SAS, Morais APP, Menezes EAV. Atenção à saúde bucal das Pessoas que Vivem com HIV/AIDS na perspectiva dos cirurgiões-dentistas. *Saúde Debate*. 2015;39(106):730-47. doi: /10.1590/0103-1104201510600030014
 35. Campos KFC, Sena RR, Silva KL. Permanent professional education in healthcare services. *Esc Anna Nery*. 2017;21(4):e20160317. doi: 10.1590/2177-9465-ean-2016-0317
 36. Nasir EF, Marthinussen MC, Åström AN. HIV/AIDS - related attitudes and oral impacts on daily performances: a cross-sectional study of Sudanese adult dental patients. *BMC Health Serv Res*. 2013;13:335. doi: 10.1186/1472-6963-13-335
 37. Pires FS, Botazzo C. Technological organization in oral health in SUS: an archeology of national policy for oral health. *Saúde Soc*. 2015;24(1):273-84. doi: 10.1590/S0104-12902015000100021
 38. Metsch LR, Pereyra M, Messinger S, Jeanty Y, Parish C, Valverde E, et al. Effects of a brief case management intervention linking people with HIV to oral health care: Project SMILE. *Am J Public Health*. 2015;105(1):77-84. doi: 10.2105/AJPH.2014.301871
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