

‘A part of me knew this would happen one day’: experiences of young people with HIV/AIDS

‘Uma parte de mim sabia que isso aconteceria um dia’: vivências de jovens com HIV/aids

Beatriz Sousa da Fonseca¹, Thamires Fernandes Cardoso da Silva Rodrigues¹, Guilherme Malaquias Silva¹, Rosângela Aparecida Pimenta², Marcelo da Silva³, Marcela Demitto Furtado¹, Maria de Fátima Garcia Lopes Merino¹

DOI: 10.1590/2358-2898202414189861

ABSTRACT This study was aimed at understanding the social representations of young people living with HIV. This is a qualitative study, based on the Social Representations Theory, carried out with 16 young people in outpatient follow-up. Data were collected between May and October 2022, through semi-structured interviews. For data processing, the lexical analysis technique was used, operationalized with the aid of the IRAMUTEQ software. The representation strongly associated with the diagnosis of HIV is related to lack of knowledge, prejudice and acceptance, also presenting positive elements such as a new beginning. Classes: Positive diagnosis for HIV: the new ‘me’; HIV in the face of ignorance and stigma; and Interpersonal relationships: dialogue, acceptance and respect necessary for young people. It was understood that the social representations of young people with HIV reflect their condition in society. The data show that there are different ways of experiencing HIV, often represented by fragility, resignation, and other times by strengthening. In order to minimize the vulnerability of young people to exposure to HIV and the risks of living with stigma and social prejudice, it is necessary to adopt strategies to raise awareness about the disease and to expand the dissemination of public policies that cover this topic.

KEYWORDS Social representation. HIV. Acquired Immunodeficiency Syndrome. Young adult. Ambulatory care.

RESUMO O objetivo deste estudo foi compreender as representações sociais de jovens que vivem com o HIV. Estudo qualitativo, ancorado na Teoria das Representações Sociais, realizado com 16 jovens em acompanhamento ambulatorial. Os dados foram coletados entre maio e outubro de 2022, por meio de entrevista semiestruturada. Para o tratamento dos dados, empregou-se a técnica de análise lexical, operacionalizada com o auxílio do software Iramuteq. A representação fortemente associada ao diagnóstico de HIV está relacionada ao desconhecimento, preconceito e aceitação, apresentando, também, elementos positivos como recomeço. Classes: Diagnóstico positivo para o HIV: o ‘eu’ de agora; HIV em face do desconhecimento e do estigma; e Relações interpessoais: diálogo, acolhimento e respeito necessários aos jovens. Compreendeu-se que as representações sociais dos jovens com HIV refletem a sua condição na sociedade. Os dados deste estudo mostram que existem formas distintas de vivenciar o HIV, muitas vezes representadas pela fragilidade, pela resignação, e outras, pelo fortalecimento. A fim de minimizar a vulnerabilidade do jovem à exposição ao HIV e aos riscos de conviver com o estigma e preconceito social, fazem-se necessárias a adoção de estratégias de conscientização da sociedade sobre a doença e a ampliação da divulgação de políticas públicas que abarcam essa temática.

PALAVRAS-CHAVE Representação social. HIV. Síndrome de Imunodeficiência Adquirida. Adulto jovem. Assistência ambulatorial.

¹Universidade Estadual de Maringá (UEM) - Maringá (PR), Brasil.
beatriz.sousa.fonseca@hotmail.com

²Universidade Estadual de Londrina (UEL) - Londrina (PR), Brasil.

³Prefeitura do Município de Maringá, Ambulatório Municipal de IST/HIV/AIDS - Maringá (PR), Brasil.



Introduction

Youth is marked by several biopsychosocial transformations, such as sexual development and maturation, in addition to the presence of uncertainties and insecurities^{1,2} that, added to the fragility of access to sex education³, can contribute to the manifestation of Health Risk Behaviors (HRC)⁴.

Therefore, adolescents and young people, aged between 15 and 24 years, are characterized as a population vulnerable to infection by the Human Immunodeficiency Virus (HIV), which causes the Acquired Immunodeficiency Syndrome (AIDS). Despite the reduction in infection rates, this age group does not follow the trend⁵. In Brazil, in the last decade, there was a 74.8% increase in the number of HIV cases among individuals aged 20 to 24 years⁶.

In this scenario, the concern about HIV/AIDS infection in young people is accentuated, since, with the positive diagnosis, feelings, anxieties, and stigmas in society are evidenced, whether in the family environment or even by the individuals, interfering in their world perception, interpersonal relationships, and sexuality⁷.

Discrimination and prejudice that involve the entire health-disease process of HIV/AIDS can directly interfere with the approach to health services, access to monitoring and treatment, as well as job, education, and socialization opportunities^{8,9}.

Although Brazil was one of the pioneering countries in the creation of public health actions and policies to treat and prevent HIV/AIDS, this scenario has changed, since studies on the subject, especially with young people between 20 and 24 years old, are still incipient¹⁰⁻¹². Reflecting on the representational contents arising from the perception of young people living with HIV, combined with the singularities and repercussions in the lives of people living with the disease, is believed to contribute to the understanding of the experiences inherent to the chronicity

of HIV and AIDS and contribute to the health and quality of life of these subjects.

Given the context, and for a better understanding of the study phenomenon, the Social Representation Theory (SRT) was adopted, which is based on the premise of a social phenomenon, built from the manifestation and communication of groups, according to their experiences, conceptions, and principles originating from everyday life¹³.

The application of SRT in studies based on the understanding of the meanings attributed to the subjects, especially concerning experiences related to HIV/AIDS, allows an in-depth reflection on the symbolic constructions that permeate the personal and interpersonal relationships of young people, given that they integrate meanings and re-significance from the perspective of the individual¹⁴. Thus, this study aims to understand the social representations of young people living with HIV.

Material and methods

This is an exploratory study with a qualitative approach based on the Social Representation Theory, which seeks to address the significant construction of a common sense based on individual or collective interaction of subjects with similar characteristics¹³. This study was based on the Consolidated criteria for Reporting Qualitative Research (COREQ)¹⁵.

The study was conducted at the Municipal STI/HIV/AIDS and Viral Hepatitis Outpatient Clinic of a medium-sized municipality in southern Brazil, which serves 30 municipalities in a Regional Health Department. In the outpatient clinic, diagnosis, monitoring, counseling, medicine distribution, and guidelines for the prevention of Sexually Transmitted Infections (STIs) are carried out.

Sixteen young people, of both sexes, with HIV/AIDS in outpatient follow-up participated in the study. Participants were selected based on convenience criteria. For the eligibility of the participants, the following inclusion

criteria were adopted: age between 20 and 24 years, characterized as young people¹, diagnosed with HIV/AIDS, and who have been attending the specialized service to care for people with HIV seropositive for at least three months. Patient follow-up time is justified by the incubation period and onset of symptoms, which may take 30 to 60 days after infection¹⁶. Young people who had cognitive impairment, described in the medical record, that could hinder their participation were excluded.

Data collection was carried out between May and October 2022, according to the schedule of appointments, in a private space, in the service itself, free of noise and the traffic of people, so that the participants could reflect, feel comfortable, and have some privacy.

Refusals to participate in the research were mainly justified by the difficulty of young people in talking about the subject, due to their experiences with the disease and the social discrimination they face in their daily lives.

For the investigation, the following were used: 1) a questionnaire containing information on sociodemographic characterization, health monitoring (time of diagnosis, time between diagnosis and start of treatment, frequency of consultations, and reason for testing), and health risk behaviors (sexual partner, drug use, unsafe sexual practices, exposure to health risk behavior); 2) a semi-structured interview, to understand the representational contents of HIV; 3) a field diary, as a methodological tool to record experience and subsequent analysis of the researcher.

To make social representations emerge, there were some guiding questions, such as: What does HIV/AIDS mean in your life?; How did you feel when you learned that your test was positive?; How is/was it for you to live with HIV and share your diagnosis with people? Data were collected until saturation, that is, until the proposed objectives were achieved¹⁷.

The interviews were recorded using a digital device, transcribed in full in Microsoft Word®, and lasted, on average, 40 minutes. After this step, the media were destroyed. The content of the interviews was available to the participants, but they were not requested. Characterization data were typed and inserted in a Microsoft Excel® spreadsheet. The rigor of the study was ensured through the evaluation criteria: credibility, transferability, reliability, and compliance¹⁸.

Lexical analysis was performed using the software IRAMUTEQ (Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires) 0.7 ALFA 2.3.3.1. Initially, a text corpus was built based on the key excerpts of the interviews, which manifested the social representations attributed to the senses and meanings that encompassed the experience of young people with HIV.

Text corpus processing was carried out in seven seconds, using 71.16% of the text segments (227 of 319 segments), revealing good use of information¹⁹. The Similarity Analysis was then used, with the construction of the maximum tree²⁰, allowing the observation of representational contents and their correlation and hierarchy between the connections of the narratives of people living with HIV/AIDS.

The analysis followed the precepts of the theoretical framework adopted¹³. We analyzed the key expressions (selected excerpts from the interviews that best describe the content); the central ideas of the speeches (the synthetic formulas that are similar in the different individuals) that configure the nucleus of meaning; the anchoring (the synthetic formulas that describe the values and the belief of the answers). This analysis allowed us to understand the interviews as a speech representative of a group (young people with HIV/AIDS).

The study followed the ethical guidelines established in Resolutions No. 466/2012²¹ and No. 510/2016²² of the National Health

and Complementary Council and was approved by the Research Ethics Committee of the signatory institution, under CAAE No. 48980821.5.0000.0104 and opinion No. 5.202.623/2022. All participants were invited to read and sign the Informed Consent Form (ICF), in two copies of equal content. To keep the participants anonymous, the letter J [for *jovem* (young) in Portuguese] was adopted, followed by the number corresponding to the order of the interviews (Example: J 10).

Results

In order to learn more about the experience of young people with HIV/AIDS and understand their social representations, the 16 participants were characterized. They were between 20 and 24 years old, with a predominance of men (14); homosexuals (10); single (12); with more than eight years of academic background (14); self-declared whites (8). Among

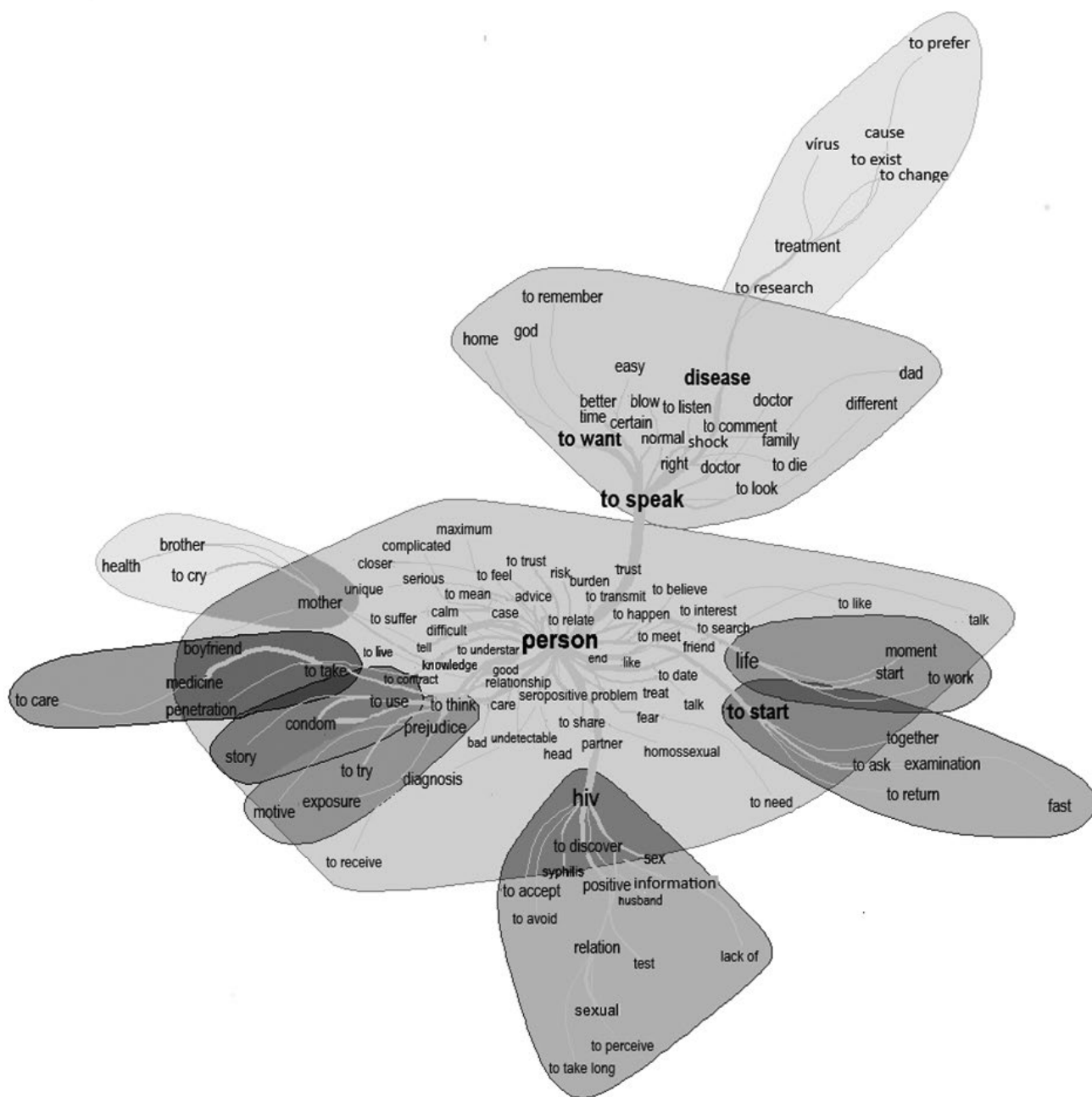
the participants, six lived with their parents.

Concerning clinical follow-up, ten young people reported that they received the diagnosis between two and six years before they were approached; twelve started treatment before completing the first year of diagnosis, and nine attended appointments over more than six months. As the main reason for testing (positive diagnosis), seven performed routine rapid tests. The HIV transmission routes were: sexual route (10), vertical transmission (1), lack of knowledge of the route (5).

The health risk behaviors of these young people were non-use of condoms during sex (8) and drug use (7).

The similarity analysis is shown below (*figure 1*), which makes it possible to identify the occurrences between the words spoken by the participants and their dimensions. Their words reflect their experience with the virus.

Figure 1. Tree showing the similarity analysis regarding the text corpus of the interview conducted with young people with HIV/Aids. Maringá, Paraná, Brazil, 2023



Source: Organized by the software IRAMUTEQ®.

This representation revealed that young people brought elements that place them as a 'person', as a central nucleus.

From the similarity analysis, young people brought terms related to the organization of hypothetical classes, starting from the central terms, integrating other nuclei, through the structural analysis proposed by the maximum tree.

The hierarchical connection between the representational terms originated classes, which lead to the discussion of the content grasped: Positive diagnosis for HIV: the new 'me'; HIV in the face of ignorance and stigma; and Interpersonal relationships: dialogue, acceptance, and respect necessary for young people.

When seeking the social representations of HIV, it is necessary to understand that young people yearn for belonging in society and being accepted as people, regardless of their condition. The sense for the various meanings attributed to the condition of having HIV/AIDS are identified by the central nucleus, when the person, inserted in a certain social context and in their interpersonal relationships, realizes the difficulty in living with the disease and everything that surrounds their condition.

The peripheral systems portray the presence of HIV, its coping and acceptance, the initiative of starting again despite the disease, preventive care and disease care, the family as a support, dialogue, and support network for sharing their condition, health care, and the need for behavior change.

Class 1: Positive diagnosis for HIV: the new 'me'

HIV in young people's lives takes a long road, ranging from the revelation of their diagnosis to their current reality. The empirical data described in the narratives reveal the feelings that permeate the lives of the subjects, with frustration and disappointment with themselves, until the understanding and acceptance

of their diagnosis, enabling an awakening to self-care, considering the fragility of sexual knowledge associated with situations of vulnerability and virus infection.

From the reports, it was possible to grasp, from the perspective of the young people, the difficulty that living with HIV imposed at first, having to understand life despite HIV, triggering self-knowledge and acceptance of their condition.

The disease itself, for me, does not mean anything and does not discourage me to live... to want to grow, to conquer what I want. Quite the contrary. (J14).

[...] today I can talk... about my illness. (J7).

Today I feel strong, a warrior, it's a learning experience... I like to tell people my story. I'm not afraid to tell, and it's a motivation. (J1).

In relation to accepting the diagnosis, there was nothing I could do, I was already positive [...]. (J3).

In the young people's speeches, which involved affective relationships, a duality of feelings was observed, which varied between trust and the absence of it in relationships. A change in behavior due to self-care was observed in most participants, seeking a greater connection between intimacy and safety, denoting self-care.

[...] I wasn't lucky enough because my partner did not tell me (about the disease), and I ended up being infected, [...] we can't trust everyone... (J12).

My boyfriend said that it could have been my ex who had infected me with (HIV)... and after we broke up, I found out that he was the one who had infected me. (J3).

You should pay attention to whom you hang out with because not all people will do you good, they want to harm you. (J2).

Class 2: HIV in the face of ignorance and stigma

The person is placed as a central focus of representations of living with HIV. The subjective elements that permeated the experience of those living with HIV were portrayed at the time of discovery of the virus infection. They expressed their emotions in the form of fear, insecurity, hopelessness and also strengthening – what they felt.

I was destroyed..., I thought I was going to die instantly, in a few days... (J2).

Deep down, a part of me knew that this would happen one day because I was very irresponsible about it [...] hearing that [diagnosis] has blown my mind. (J6).

At first, it means death, having to give up everything... (J7).

[...] it was a moment of adaptation and appreciation of my personal life. (J14).

For people with HIV/AIDS, experiencing prejudice represents social exclusion. There was a strong connection between the subjective elements associated with the stigma that permeates the lives of people living with the disease.

[...] people are not open to learning more about HIV, to knowing what it is like to live with an undetectable person, what it is like to relate... if you say you are HIV seropositive, it already causes some sort of astonishment and strangeness. (J3).

My greatest difficulty at the beginning was the fear of exposure, prejudice, and everything that we would carry for the rest of our lives. (J14).

The speeches point to the lack of guidance and knowledge about sexual health and the adoption of healthy and preventive behaviors – accountability.

My lack of knowledge, ignorance, made me have attitudes such as unprotected sex, which led to the disease. (J9).

HIV still brings the 1980s/1990s' ideas that people diagnosed with HIV had received their death sentence. There is a lack of information. (J14).

Researching more about the disease... most people do not have much knowledge about how it is transmitted, about how an HIV-positive person lives their life. There are many people who still think that the diagnosis of HIV is a death sentence, as it was in the past. I think this can help a lot. (J8).

Class 3: Interpersonal relationships: dialogue, acceptance, and necessary respect for young people

Families are related to acceptance, although it is not always represented in this way. Young people's speeches are also marked by the association between the experience of the disease and family relationships. There was a strong connection between person, mother, and cry. The maternal figure is related to care, acceptance, and support, constantly present in the speeches of young people – they want to be accepted as a person.

[...] When I came back home... after a while, I told my mother. (J8).

I feel really sad. I almost got depressed. At first, I didn't want to accept it, but I had a lot of support from my mother. (J12).

[...] My mother and father, likewise, always support me in my treatment, they never even pointed the finger at me and said, 'look, you were wrong'. Quite the contrary, they accepted me even more. (J2).

The vulnerabilities that are intrinsic to the youth can directly interfere with their health. In general, risk behaviors are linked to

affective relationships, and therefore, knowledge can help in maintaining a healthy life.

[...] even though you have a boyfriend... Even though you love him, I think we should take more care of ourselves [...]. (J12).

[...] they are going to take advantage of your innocence or because you are having a happy moment... So, be careful with the people you walk with and always take the test. (J2).

The hesitation to reveal one's serological tests to partners highlights a conflict between the fear of risking the relationship by being transparent and the desire to protect these bonds from the potential judgment that sharing this information could provoke.

When the person doesn't know [about HIV], you feel a little uncomfortable, you know? Like, even though you have safe sex, it gets kind of uncomfortable. (J4).

I intend to share [the diagnosis] when I am in a serious [relationship] with a person. (J8).

I try to share with partners when I think it is necessary to do so. Otherwise, as I am aware that I am undetectable... (J14).

The speeches demonstrated the importance of disseminating information about HIV to the population and, especially, among young people. In this class, the social representations of scientific knowledge and common sense about HIV/AIDS and how it is transmitted, prevention mechanisms, and forms of treatment emerged – what is known about HIV.

[...] using a condom could reduce, like almost to zero, the risk of getting any disease. (J8).

I don't know if the problem was the fact that I am gay... being gay and not having access... not talking to other people about sex, because gay sex is different from straight sex. (J9).

Discussion

The speeches reveal a complex and sometimes contradictory view of the strategies for coping with HIV/AIDS experienced by the young people in the study. There is a fatalistic version as to the virus infection and also the possibility of living with it without harm to life. The search for self-acceptance and the acceptance of family and partners is associated with the fear of social rejection, depending on their condition.

At first, HIV and AIDS were anchored by young people as a fatal disease. Sharing their condition was directly related to discrimination; having contracted the virus was reconnected to carelessness with health; living with the disease was a determinant to expose others to the risk of getting sick. They also associated the disease with homosexuality, lack of care for their own bodies, and recklessness in their choices in affective relationships.

After the diagnosis, the young people became more responsible for their health and relationships. Some identified the need for preventive practices, but at certain times, they are neglected by external limitations related to the partner's ability to understand, which is in line with their representations of the disease. Many still have the perception that such measures are unnecessary, because they are considered undetectable.

It is noteworthy that scientific knowledge about the suppression of viral load in HIV transmissibility, even today, needs greater dissemination among people as a whole. An important step in this direction was the Access Campaign Prevention Program, which, in 2016, launched the U=U (undetectable equals untransmittable) campaign, which stated that people living with HIV and having an undetectable viral load do not transmit HIV to their partners²³. This disclosure is necessary to encourage early testing and treatment and to combat the stigma and discrimination that continue to affect people living with HIV.

In this sense, daily experiences are lived with greater intensity and convey impressions that seem more real. Situations that occur on a daily basis are perceived in greater detail than others experienced sporadically. Therefore, the greater the importance of the social object for the group, the greater will be the reflection of the group on it²⁴.

Through the central nucleus, the presence of two representational structures within the group was identified: the first has as its central nucleus the concepts of non-acceptance and resilience; the second one has to do with speaking after the diagnosis of HIV, which, despite being an incurable disease, conceives the condition of a normal life with quality. When faced with a positive diagnosis for the virus, the feelings passed on to young people are translated as determinants of their health condition. Since the 1980s, the representations have perpetuated to the present day, highlighting the weaknesses regarding knowledge about access to preventive, guiding, and diagnostic actions for HIV, AIDS, and other STIs^{25,26}.

Being young implies reaffirming a cycle of discovery, development, and planning for the future. Sexuality, in turn, better evidenced in this age group, represents a moment of exploration of freedom and autonomy. When young people adopt behaviors detrimental to their physical integrity, they provide opportunities for exposure to diseases and risks that can be determinant throughout their lives²⁷.

In addition to the physical damage caused by the disease, people with HIV face feelings of guilt, judgment, and fear of non-acceptance by society and the family²⁸. In addition, many subjects who have a positive diagnosis of the disease are faced with discouragement, loss of perspective, and goals pre-established by them²⁹. In addition, there are different behaviors, in which some individuals postpone the search for health services because they anticipate the possibility of suffering discrimination, mainly because they do not accept the disease or do not understand the process that involves HIV/AIDS.

In this scenario, clinical follow-up and late treatment can contribute to the advancement of the disease, resulting in the rapid onset of symptoms and the debilitation of the individual³⁰. In addition, patients with HIV can develop depression, which shows that the pathology can also have a psychological/mental burden³¹.

Family functionality can have constructive or destructive family relationships for people living with HIV³². In effective communication in the relationship between doctors/nurses and the patient, there is clarity in the health and disease process, which can be expanded to the family environment, so that there is a collective education, with the breaking of stigmas generated throughout the years of HIV³³. However, it is imperative to recognize that, ideally, while breaking stigmas within health services and the family represents an advance, prejudices and resistances persist, often from healthcare providers themselves, who should act as pillars of support and information¹⁴.

It should be considered that health professionals, by integrating their religious convictions and beliefs into care practices, can contribute to the blaming of individuals infected with HIV³⁴. To this end, health services should seek greater accessibility, openness, reduction of bureaucracy and flexibility, aiming to welcome and meet individual needs, fostering personalized care³⁴.

The testimonies denote a view that, by adopting preventive measures, young people avoided the suffering they experienced. Still regarding this, it is clear that affective and sexual relationships are intrinsically affected after the diagnosis of HIV. These antagonistic positions are expected, since it is in the consensual universe, in the interactions present in everyday practices, that social representations are built, and they are determined from the situations experienced in the known and familiar environment³⁵. Thus, these feelings can significantly influence the individual's sexuality, resulting in a tendency to reduce affective and sexual relationships. In addition,

deeper engagement between subjects may culminate in sharing the diagnosis, leading to partner loss or discrimination³⁶.

However, it is important to highlight the need to manage interpersonal relationship support networks, since they are essential for coping with the disease, promoting better living conditions and social practices. In addition, it is noteworthy that social support, whether family, friends, or partners, can be an excellent tool for these young people to feel included, overcome the situation and minimize the negative effects arising from the diagnosis³⁷.

In this panorama of support and reception for people living with HIV, support groups in applications such as WhatsApp, Facebook, and Telegram, where participants can highlight their experiences with HIV, are a safe zone for prejudices arising from individuals, which stands out as one of the support networks for young people³⁸.

Since the first discussions about the origin of the disease, stigma, and discrimination have been irreversibly produced, marked, and reinforced, and, consequently, the subject infected by the HIV, as well^{26,27}. In the current scenario, the virus still carries many stigmas within society, becoming a great challenge for individuals living with the pathology, and this alienation of the population on the subject exacerbates prejudice and discrimination³⁴.

Such prejudice currently derives from the associations with the epidemic in the 1980s, since, in the beginning, they related the virus to homosexuals, hemophiliacs, Haitians, drug users, and sex workers, that is, to marginalized groups³⁹. Thus, the fear of being judged often leads infected subjects to hide the diagnosis as a strategy to minimize their social impact^{34,40}.

The discovery of HIV is a difficult process, often linked to feelings of indignation/sadness, given that the social relationship is a complicating factor for patients with the disease, as the virus infection can be a stigmatizing health condition, which involves feelings of discrimination and, consequently,

lack of social support and feelings of loneliness³⁹. In addition, the number of young patients living with HIV is growing, and this is accompanied by a high prevalence of depressive signs and symptoms. From this perspective, social and family support are protective factors for the quality of life and mental health of those affected⁴¹.

Thus, young people living with HIV may have their self-esteem altered, as a social impact is caused due to the virus infection. Self-esteem influences the way individuals think, whether positively or negatively, beyond the limits imposed by the disease, such as breaking ties, discrimination, fragile life projects, and changes in habits and lifestyle⁴².

In order to positively interfere, health services, together with other support networks, must intervene in the universe experienced by young people, bringing information from the scientific world, objectivity, and abstract theorizations – the unfamiliar, such as HIV, to a meaning already known to people. These services should seek to create a bond with young people through qualified dialogue, transmitting scientific knowledge about prevention, diagnosis, and care of individuals with HIV⁴³.

Information about HIV is a key factor in increasing adherence to treatment and, consequently, improving the quality of life of infected people. Understanding the causes, symptoms, and forms of treatment of the disease is essential to face the stigma and prejudice associated with it, in addition to promoting the prevention of virus transmission⁴². Therefore, the provision of health knowledge in different contexts can contribute to behavior change, minimizing the social impacts of HIV and providing a better quality of life to the population⁴³.

The limitations of the study are based on the adherence of the participants. Considering that the topic is permeated by stigma, the fear of prejudice and/or judgments made most of the people approached to refuse to share their experiences.

Final considerations

The social representations of HIV developed by young people are an interpretation of their reality, of those who live with the virus and the disease, based on their infection. In this context, they sought ways to experience their condition in the social space in which they are inserted, often perceiving themselves in a singular group, as HIV positive. The findings reveal the complexity of the health-disease process of young people living with HIV. Therefore, when they acquire knowledge about their health condition, they begin to perceive the opportunity to increase their expectation and improve their quality of life.

It is noteworthy that the evidence of this research is related to the stigmas and prejudices that are still present in today's society; the acceptance of the disease and the importance of treatment, based on the knowledge guided by the specialized care service; the weaknesses inherent in the process of sexual education grasped from adolescence to young age, in addition to the support network as the main mechanism for coping with the disease.

It is imperative to question the gaps in the health follow-up of the young population. As much as there are public policies aimed at prevention and health promotion, there are significant flaws in their execution and professional performance, which contribute to the vulnerability of these individuals. To this end,

it is urgent that managers and governments assume their leadership role in responding to the epidemic, adopting effective measures to address the underlying causes of the spread of HIV and ensuring the well-being and dignity of all people affected by this condition.

Collaborators

Fonseca BS (0000-0002-3469-2231)* and Merino MFGL (0000-0001-6483-7625)* also contributed to the manuscript preparation, conception, and design of the work; data collection, analysis, and interpretation; writing of the article and its critical review; and final approval of the version to be published. Rodrigues TFCs (0000-0001-7942-4989)* contributed to data collection, analysis, and interpretation; and final approval of the version to be published. Silva GM (0000-0003-4748-2951)* contributed to the writing of the article and its critical review; and final approval of the version to be published. Silva M (0000-0002-0376-0430)* contributed to the conception and design of the work; and final approval of the version to be published. Pimenta RA (0000-0003-0157-7461)* and Furtado MD (0000-0003-1427-4478)* also contributed to the conception and design of the work; writing of the article and its critical review; and final approval of the version to be published. ■

*Orcid (Open Researcher and Contributor ID).

References

1. World Health Organization. Older adolescent (15 to 19 years) and young adult (20 to 24 years) mortality. 2022. [acesso em 2022 out 25]. Disponível em: [https://www.who.int/news-room/fact-sheets/detail/levels-and-trends-in-older-adolescent-\(15-to-19-years\)-and-young-adult-\(20-to-24-years\)-mortality](https://www.who.int/news-room/fact-sheets/detail/levels-and-trends-in-older-adolescent-(15-to-19-years)-and-young-adult-(20-to-24-years)-mortality).
2. Silva CBD, Bellenzani R, Motta MGC. Experience of pregnancy and maternity by adolescents/young people born infected with HIV. *Rev. Bras. Enferm.* 2020 [acesso em 2022 out 24]; 73(supl4):e20190405. Disponível em: <https://doi.org/10.1590/0034-7167-2019-0405>.
3. Guedes DP, Zuppa MA. Propriedades psicométricas da versão brasileira da Adolescent Health Promotion Scale (AHPS). *Ciênc. saúde coletiva.* 2020 [acesso em 2023 out 10]; 25(6):2357-68. Disponível em: <https://doi.org/10.1590/1413-81232020256.23252018>.
4. Moura LR, Torres LM, Cadete MMM, et al. Fatores associados aos comportamentos de risco à saúde entre adolescentes brasileiros: uma revisão integrativa. *Rev. Esc. Enferm. USP.* 2018 [acesso em 2022 dez 15]; 52:e03304. Disponível em: <http://dx.doi.org/10.1590/S1980-220X2017020403304>.
5. Brasil. Ministério da Saúde, Secretaria de Vigilância em Saúde. *Boletim Epidemiológico HIV/Aids 2021*. Brasília, DF: MS, 2021. [acesso em 2022 out 25]. Disponível em: <https://www.gov.br/saude/pt-br/centrais-de-conteudo/publicacoes/boletins/epidemiologicos/especiais/2021/boletim-epidemiologico-especial-hiv-aids-2021.pdf/view>.
6. Brasil. Ministério da Saúde, Secretaria de Vigilância em Saúde. *Boletim Epidemiológico HIV/Aids 2020*. Brasília, DF: MS; 2020. [acesso em 2022 out 25]. Disponível em: <https://www.gov.br/saude/pt-br/centrais-de-conteudo/publicacoes/boletins/epidemiologicos/especiais/2020/boletim-hiv-aids-2020-internet.pdf>.
7. Lobo AS, Leal MAF. A revelação do diagnóstico de HIV/Aids e seus impactos psicossociais. *Rev. Psicol. Divers Saúde.* 2020 [acesso em 2022 nov 1]; 9(2):174-89. Disponível em: <https://doi.org/10.17267/2317-3394rpsds.v9i2.2833>.
8. Ew RAS, Ferreira GS, Moro LM, et al. Estigma e teste rápido na atenção básica: percepção de usuários e profissionais. *Rev. Bras. Promoç. Saúde.* 2018 [acesso em 2022 nov 1]; 31(3):1-9. Disponível: <https://doi.org/10.5020/18061230.2018.7463>.
9. Rossi AM, Souza RKT, Corrêa LFL, et al. Positividade ao HIV e fatores associados em um centro de testagem e aconselhamento. *Ciênc. Cuid. Saúde.* 2021 [acesso em 2022 out 26]; 20:e50495. Disponível em: <https://doi.org/10.4025/ciencuidsaude.v20i0.50495>.
10. Silva DPE, Oliveira DC, Marques SC, et al. Social representations of the quality of life of the young people living with HIV. *Rev. Bras. Enferm.* 2021 [acesso em 2022 nov 1]; 74(2):e20200149. Disponível em: <https://doi.org/10.1590/0034-7167-2020-0149>.
11. Silva RG, Abreu PD, Araújo EC, et al. Vulnerability in the health of young transgender women living with HIV/Aids. *Rev. Bras. Enferm.* 2020 [acesso em 2022 nov 5]; 73(5):e20190046. Disponível em: <https://doi.org/10.1590/0034-7167-2019-0046>.
12. Braga RMO, Lima TP, Gomes AMT, et al. Representações sociais do HIV/Aids para as pessoas que convivem com a síndrome. *Rev. Bras. Enferm.* 2016 [acesso em 2022 nov 5]; 24(2):e15123. Disponível em: <http://dx.doi.org/10.12957/reuerj.2016.15123>.
13. Zalfa LMC, Espirito-Santo G, Assis MR. Representação social sobre saúde em uma escola no Rio de Janeiro. *Rev. Bras. Educ. Fís. Esporte.* 2020 [acesso em 2022 nov 5]; 34(4):611-21. Disponível em: <http://dx.doi.org/10.11606/1807-5509202000040611>.

14. Machado YY, Silva AL, Albuquerque VS, et al. Representações sociais dos profissionais de saúde sobre HIV/Aids: comparação entre homens e mulheres. *Saúde e Pesqui.* 2020 [acesso em 2022 nov 5]; 13(4):861-69. Disponível em: <https://doi.org/10.17765/2176-9206.2020v13n4p861-869>.
15. Souza VRS, Marziale MHP, Silva GTR, et al. Tradução e validação para a língua portuguesa e avaliação do guia COREQ. *Acta Paul Enferm.* 2021 [acesso em 2022 out 25]; 34:eAPE02631. Disponível em: <https://doi.org/10.37689/acta-ape/2021AO02631>.
16. Neto LFSP, Perini FB, Aragón MG, et al. Protocolo Brasileiro para Infecções Sexualmente Transmissíveis 2020: infecção pelo HIV em adolescentes e adultos. *Epidemiol. Serv. Saúde.* 2021 [acesso em 2022 nov 5]; 30(esp1):e2020588. Disponível em: <https://doi.org/10.1590/S1679-4974202100013.espl>.
17. Oliveira DC. Análise de conteúdo temático-categorial: uma técnica maior nas pesquisas qualitativas. In: Lacerda MR, Costenaro RGS, editores. *Metodologia da pesquisa para a Enfermagem e Saúde: da teoria à prática.* Porto Alegre: Moriá; 2016.
18. Guba EG, Lincoln YS. Paradigmas concorrentes em pesquisa qualitativa. In: Denzin NK, Lincoln YS, editores. *O Cenário da Pesquisa Qualitativa.* Thousand Oaks: Sage; 1989.
19. Moura RM, Motokane MT, Oliveira MM. Síntese interativa através da construção de texto colaborativo subsidiado pelo IRAMUTEQ no âmbito da metodologia interativa. *Div. Journ.* 2022 [acesso em 2022 nov 3]; 7(1):476-494. Disponível em: <https://doi.org/10.48017/dj.v7i1.2018>.
20. Marchand P, Ratinaud P. L'analyse de similitude appliquée aux corpus textuels: les primaires socialistes pour l'élection présidentielle française (septembre-octobre 2011). *Actes Des 11èmes Journées Internationales d'Analyse Des Données Textuelles (JADT) 2012.* [acesso em 2022 out 25]. Disponível em: <http://lexicometrica.univ-paris3.fr/jadt/jadt2012/Communications/Marchand,%20Pascal%20et%20al.%20-%20L'analyse%20de%20similitude%20appliquee%20aux%20corpus%20textuels.pdf>.
21. Brasil. Resolução nº 466, de 12 de dezembro de 2012. Dispõe sobre diretrizes e normas regulamentadoras de pesquisas envolvendo seres humanos. *Diário Oficial da República Federativa do Brasil, Brasília, DF, 12 dez 2012.* [acesso em 2022 out 23]. Disponível em: <https://conselho.saude.gov.br/resolucoes/2012/Reso466.pdf>.
22. Brasil. Resolução nº 510, de 07 de abril de 2016. Dispõe sobre as normas aplicáveis a pesquisas em Ciências Humanas e Sociais. *Diário Oficial da República Federativa do Brasil, Brasília, DF, 7 abr 2016.* [acesso em 2022 out 23]. Disponível em: https://bvsms.saude.gov.br/bvs/saudelegis/cns/2016/res0510_07_04_2016.html.
23. Rodger AJ, Cambiano V, Bruun T, et al. Risk of HIV transmission through condomless sex in serodifferent gay couples with the HIV-positive partner taking suppressive antiretroviral therapy (PARTNER): final results of a multicentre, prospective, observational study. *Lancet.* 2019 [acesso em 2024 mar 27]; 393(10189):2428-2438. Disponível em: [https://doi.org/10.1016/S0140-6736\(19\)30418-0](https://doi.org/10.1016/S0140-6736(19)30418-0).
24. Berger PL, Luckmann T. A construção social da realidade: tratado de sociologia do conhecimento. 24. ed. Petrópolis: Vozes; 2004.
25. Alves IN, Pires Filho LAS, Salviano ACS, et al. Perfil epidemiológico de adultos jovens (20 a 24 anos) com HIV/Aids em uma cidade do interior paulista. *REAS.* 2020 [acesso em 2023 fev 23]; (57):e4164. Disponível em: <https://doi.org/10.25248/reas.e4164.2020>.
26. Muniz CG, Brito C. O que representa o diagnóstico de HIV/Aids após quatro décadas de epidemia? *Saúde debate.* 2022 [acesso em 2023 fev 25]; 46(135):1093-106. Disponível em: <https://doi.org/10.1590/0103-1104202213510>.

27. Fernandes I, Bruns MAT. Revisão sistematizada da literatura científica nacional acerca da história do HIV/Aids. *Rev. Bras. Sex. Hum.* 2021 [acesso em 2023 fev 25]; 32(1):60-7. Disponível em: <https://doi.org/10.35919/rbsh.v32i1.916>.
28. Vinagre MG, Barros L. Preferências dos adolescentes sobre os cuidados em saúde. *Ciênc. saúde coletiva.* 2019 [acesso em 2023 fev 25]; 24:1627-36. Disponível em: <https://doi.org/10.1590/1413-81232018245.04362019>.
29. Cruz MLS, Darmont MQR, Monteiro SS. Estigma relacionado ao HIV entre jovens em transição para a clínica de adultos num hospital público no Rio de Janeiro, Brasil. *Ciênc. saúde coletiva.* 2021 [acesso em 2023 fev 23]; 26(7):2877-86. Disponível em: <https://doi.org/10.1590/1413-81232021267.07422021>.
30. Patrício ACFA, Silva IBN, Ferreira MAM, et al. Depression, self-concept, future expectations and hope of people with HIV. *Rev. Bras. Enferm.* 2019 [acesso em 2023 fev 20]; 72(5):1288-94. Disponível em: <http://dx.doi.org/10.1590/0034-7167-2018-0730>.
31. Souza LS, Santos NP, Lima PV, et al. Evaluation of family functionality in elderly people living with HIV/AIDS. *São Paulo: Rev. Recien.* 2021 [acesso em 2022 out 25]; 11(33):99-106. Disponível em: <https://doi.org/10.24276/rrecien2021.11.33.99-106>.
32. Oliveira DC, Stefaisk RLM, Machado YY, et al. Rebuilding oneself with HIV: practices for promoting quality of life revealed by research. *Rev. Saber Digital.* 2022 [acesso em 2023 fev 24]; 15(3):e20221515. Disponível em: <https://doi.org/10.24859/SaberDigital.2022v15n3.1347>.
33. Rocha LF. Teoria das representações sociais: a ruptura de paradigmas das correntes clássicas das teorias psicológicas. *Psico ciênc. prof.* 2014 [acesso em 2023 jan 2]; 34(1):46-65. Disponível em: <https://doi.org/10.1590/S1414-98932014000100005>.
34. Melo EA, Maksud I, Agostini R. Cuidado, HIV/Aids e atenção primária no Brasil: desafio para a atenção no Sistema Único de Saúde? *Rev. Panam. Salud Publica.* 2018 [acesso 2022 dez 15]; 42:e151. Disponível em: <https://doi.org/10.26633/RPSP.2018.151>.
35. Sá AAM, Santos CVM. A vivência da sexualidade de pessoas que vivem com HIV/Aids. *Psico ciênc. prof.* 2018 [acesso em 2023 fev 23]; 38(4):773-86. Disponível em: <https://doi.org/10.1590/1982-3703000622017>.
36. Silva RTS, Silva RAR, Rodrigues IDC, et al. Coping strategies of people living with AIDS in face of the disease. *Rev. Latino-Am. Enfermagem.* 2018 [acesso em 2024 mar 27]; 26:e2985. Disponível em: <https://doi.org/10.1590/1518-8345.2284.2985>.
37. Nunes Junior SS, Ciosak SI. Terapia antirretroviral para hiv/aids: o estado da arte. *Revista de Enfermagem UFPE on line.* 2018 [acesso em 2022 out 25]; 12(4):1103. Disponível em: <https://periodicos.ufpe.br/revistas/index.php/revistaenfermagem/article/view/231267>.
38. Cunha CC, Stochero L, Almeida LA, et al. Na encruzilhada de duas pandemias: a experiência de redes de apoio social de jovens e adultos vivendo com HIV/Aids durante a pandemia de Covid-19. *Physis.* 2022 [acesso em 2024 mar 27]; 32(3):e320301. <https://doi.org/10.1590/S0103-73312022320301>.
39. Pimentel GS, Ceccato MGB, Costa JO, et al. Qualidade de vida em indivíduos iniciando a terapia antirretroviral: um estudo de coorte. *Rev. Saúde Pública.* 2020 [acesso em 2023 mar 24]; 54:146. Disponível em: <https://doi.org/10.11606/s1518-8787.2020054001920>.
40. Melo DS, Mello R. Representações sociais de pessoas vivendo com HIV: autopercepção da identidade egoecológica. *Saúde debate.* 2021 [acesso em 2023 mar 24]; 45(131):1101-10. Disponível em: <https://doi.org/10.1590/0103-1104202113112>.
41. Magno L, Silva LAV, Veras MA, et al. Estigma e discriminação relacionados à identidade de gênero e à vulnerabilidade ao HIV/aids entre mulheres transgênero: revisão sistemática. *Cad. Saúde*

Pública. 2019 [acesso em 2024 mar 27]; 35(4):e-00112718. Disponível em: <https://doi.org/10.1590/0102-311X00112718>.

Rev. Saúde Pública. 2019 [acesso em 2024 mar 27]; 53:80. Disponível em: <https://doi.org/10.11606/s1518-8787.2019053001174>.

42. Freitas JD, Maciel RHMO. HIV/AIDS: evolução e depressão em pessoas soropositivas: uma revisão narrativa. REAS. 2021 [acesso em 2023 fev 24]; 13(5):e7441. Disponível em: <https://doi.org/10.25248/reas.e7441.2021>.

Received on: 10/27/2023
Approved on: 04/23/2024
Conflict of interests: non-existent
Financial support: Coordination for the Improvement of Higher Education Personnel - Brasil (CAPES) - Financing code 001. (Process No.: 88887.61581/2021-00)

Responsible editor: Jamilli Silva Santos

43. Taquette SR, Souza LMBM. HIV-AIDS prevention in the conception of HIV-positive young people.