Research Article
Artigo de Pesquisa
Artículo de Investigación

DOI: https://doi.org/10.12957/reuerj.2025.87192

Young people living with HIV: perceptions of healthcare follow-up in light of vulnerability concepts

Jovens vivendo com HIV: Percepções sobre o acompanhamento em saúde à luz dos conceitos de vulnerabilidades

Jóvenes que viven con VIH: Percepciones sobre el seguimiento en salud a la luz de los conceptos de vulnerabilidades

Beatriz Sousa da Fonseca[I]; *Thamires Fernandes Cardoso da Silva Rodrigues*[I]; *Guilherme Malaquias Silva*[I]; *Liane Alves de Sá*[I]; *Camila Moraes Garollo Piran*[I]; *Rosangela Aparecida Pimenta*[II]; *Marcela Demitto Furtado*[I]; *Maria de Fátima Garcia Lopes Merino*[I]

[I]*Universidade Estadual de Maringá. Maringá, PR, Brazil;* [II]*Universidade Estadual de Londrina. Londrina, PR, Brazil*

ABSTRACT

Objective: to understand the perceptions of young people living with HIV regarding healthcare follow-up. **Method:** a qualitative study grounded in the Concepts of Vulnerability, conducted with 16 young people aged 20 to 24 years who were periodically followed in a specialized health service. Data collection took place between May and October 2022 through in-depth interviews, followed by lexical analysis using the IRaMuTeQ® software. The research protocol was approved by an Ethics Committee. **Results:** the findings shed light on the complex realities experienced by young people living with HIV, marked by vulnerabilities and stigmatization. They highlight the essential role of health services and support networks in coping with their condition—from diagnosis and initial support to continuous follow-up. **Final considerations:** the persistence of discrimination reinforces the need for health education as a means to promote health, self-care, and prevention.

Descriptors: Health Services; Continuidade da Assistência ao Paciente; Health Vulnerability; HIV; Young Adult.

RESUMO

Objetivo: compreender a percepção dos jovens que vivem com HIV sobre o acompanhamento em saúde. **Método:** estudo qualitativo, ancorado nos Conceitos de Vulnerabilidades, desenvolvido com 16 jovens entre 20 e 24 anos, acompanhados periodicamente em serviço de saúde especializado. A coleta de dados ocorreu no período de maio a outubro de 2022, por meio de entrevista em profundidade e posterior análise lexical com auxílio do software IRaMuTeQ®. Protocolo de pesquisa aprovado por Comitê de Ética. **Resultados:** os resultados trazem à luz realidades complexas percebidas por jovens vivendo com HIV, marcadas por vulnerabilidades e estigmatização, destacando o papel dos serviços de saúde e das redes de apoio como essenciais para o enfrentamento da sua condição, desde o diagnóstico, acolhimento até o acompanhamento continuado. **Considerações finais:** a persistência da discriminação reforça a necessidade de educação em saúde como meio de promoção da saúde, autocuidado e prevenção.

Descritores: Serviços de Saúde; Continuidade da Assistência ao Paciente; Vulnerabilidade em Saúde; HIV; Adulto Jovem.

RESUMEN

Objetivo: analizar la percepción de los jóvenes con VIH respecto al seguimiento en salud que reciben. **Método:** estudio cualitativo, basado en los Conceptos de Vulnerabilidades, desarrollado con 16 jóvenes de 20 a 24 años, en seguimiento periódico en un servicio de salud especializado. La recolección de datos se llevó a cabo entre mayo y octubre de 2022, por medio de entrevistas en profundidad y posterior análisis léxico con el apoyo del software IRaMuTeQ®. El Comité de Ética aprobó el protocolo de investigación. **Resultados:** los resultados ponen de manifiesto realidades complejas percibidas por jóvenes que viven con VIH, marcadas por vulnerabilidades y estigmatización, destacando el papel de los servicios de salud y de las redes de apoyo como esenciales para enfrentar su condición, desde el diagnóstico y la acogida hasta el seguimiento continuo. **Consideraciones finales:** la persistencia de la discriminación refuerza la necesidad de la educación en salud como medio de promoción de la salud, autocuidado y prevención.

Descriptores: Servicios de Salud; Continuidad de la Atención al Paciente; Vulnerabilidad en Salud; VIH; Adulto Joven.

INTRODUCTION

Four decades after the discovery of the Human Immunodeficiency Virus (HIV), the causative agent of Acquired Immunodeficiency Syndrome (AIDS), the disease remains a pandemic—unstable and dynamic in nature—revealing constant changes in its epidemiological profile and continuing to pose a major challenge for health organizations worldwide[1].

This study was supported in part by the *Coordenação de Aperfeiçoamento de Pessoal de Nível Superior* – Brazil (CAPES) – Funding Code 001.

Corresponding Author: Beatriz Sousa da Fonseca. E-mail: beatriz.sousa.fonseca@hotmail.com

Editor-in-Chief: Cristine Helena Gallasch; Associate Editor: Antonio Marcos Tosoli Gomes

Received: Sep 10th 2024 – Accepted: Nov 27th 2025

Globally, 2023 data indicate that 39.9 million people are living with HIV[2]. In Brazil, since the emergence of the virus, 1,165,599 AIDS cases have been reported, with an average of 36.4 thousand new cases per year[3]. Although a slight downward trend in HIV infections has been observed over the years, young people—considered a vulnerable group—remain among the most affected population, with those aged 15 to 24 accounting for 23.2% of cases[4].

Risk exposure is known to be a characteristic of young people in general, and as such, the need emerges for a focused approach to their vulnerabilities across all dimensions—educational, political, economic, social, cultural, environmental, and health-related[5]. For People Living with HIV (PLHIV), all these dimensions must be considered. From this perspective, clinical monitoring of these individuals is a fundamental strategy for health follow-up and for improving access to treatment[6].

Therefore, at the national level, Brazil's Ministry of Health, through the Unified Health System (SUS), provides safe and free diagnosis and treatment, including rapid tests in primary health care units and Testing and Counseling Centers (CTA). SUS also offers prevention methods such as condoms, Pre-Exposure Prophylaxis (PrEP), and Post-Exposure Prophylaxis (PEP). For individuals already diagnosed, SUS provides treatment through clinical follow-up and antiretroviral (ARV) medications, aimed at controlling the infection and improving the quality of life of PLHIV[7].

Even though continued treatment is essential for the survival and maintenance of quality of life of individuals living with HIV, several factors may influence adherence to care following diagnosis, such as the non-acceptance of the disease, low educational level, fear of discrimination, and dissatisfaction with health services—all of which may affect a young person's decision to continue or discontinue treatment[6].

Thus, the condition of People Living with HIV (PLHIV) can be understood through the three analytical dimensions of vulnerability, concepts proposed by Mann and Tarantola in 1996, which constitute the individual, social, and programmatic theoretical framework[8-9]. The first refers to the subject's own actions, encompassing behavioral expressions and attitudes based on their level of awareness. Social vulnerability concerns the broader context in which the individual is inserted—historical, political, and economic aspects—as well as access to health resources, culture, services, and information. Programmatic vulnerability relates to strategies implemented by public and private sectors aimed at promoting effective actions and funding initiatives[10].

The vulnerability of young people living with HIV in Brazil emerges from a multiplicity of factors and meanings, reflecting human fragilities arising from inequalities, injustices, and oppression. Understanding vulnerability as a factor associated with individuals' exposure to illness reinforces the need to consider the set of individual, social, and programmatic elements, as well as the availability of protective resources against situations of risk[11].

Within this context of vulnerability, the creation of public health policies for HIV/AIDS treatment and prevention becomes especially relevant. Historically, Brazil has stood out as one of the pioneering countries in designing health-related public policies; however, the vulnerability of individuals seeking health services and follow-up care persists[12].

Since the emergence of the HIV/AIDS epidemic in the 1980s, Brazil has gained recognition for its strong response to the disease through public policies aligned with WHO recommendations, ensuring free access to antiretroviral medications and prevention campaigns. Despite these advances, challenges remain in care practices, including inequalities in access to health services and the shortage of qualified professionals[12]. Non-adherence to treatment continues to be a public health issue, influenced by the decentralization of care and sociocultural barriers[13].

Thus, the stigma surrounding HIV, rooted in the history of the disease, continues to affect community relationships and the work of health professionals. Studies show that stigma and discrimination persist in the daily lives of both users and professionals, particularly during rapid testing in primary care settings, generating concerns about ethics, confidentiality, and respect for the right to access healthcare[14]. This apprehension may discourage PLHIV from seeking health services[13].

In this context, it is necessary to reflect on the process involved in the outpatient care of young people living with HIV, based on their experiences with health services. Considering the significant increase in cases among the youth population, understanding their perceptions of healthcare follow-up, vulnerabilities, and care needs can contribute to the development of protective measures for this specific group and stimulate further research on the topic as part of a broader care strategy for this population.

Therefore, the present study aims to understand the perceptions of young people living with HIV regarding their healthcare follow-up.

METHOD

This is a qualitative, descriptive study, anchored in the conceptual approaches to vulnerabilities proposed by Ayres in 2014[11]. Qualitative research allows the investigator to highlight the socially constructed nature of reality and to explore how social experiences are created and acquire meaning for people[15]. It should be noted that the study was reported according to the recommendations of the Consolidated Criteria for Reporting Qualitative Research (COREQ)[16].

The study was conducted in a reference outpatient clinic for people with sexually transmitted infections (STIs) such as HIV/AIDS, hepatitis, and others, which serves a health region encompassing 30 municipalities. This walk-in service allows users to seek care directly, without the need for prior referral. Care is provided in a multidisciplinary manner, involving professionals from medicine, nursing, pharmacy, psychology, social work, and other areas, ensuring a comprehensive and continuous approach to patient health. The services include diagnosis, clinical and laboratory follow-up, dispensing of antiretroviral medications, counseling and psychosocial support, as well as educational and preventive activities, ensuring broad and qualified support to the population served.

A convenience sample was adopted, with potential participants approached in person after their medical and nursing appointments. The study included 16 young people aged 20 to 24 years, with a laboratory-confirmed HIV diagnosis, who had been attending the outpatient service for at least three months. This minimum period was established to ensure that participants had already established an initial bond with the multidisciplinary team and had attended at least one medical and one nursing consultation, guaranteeing the initial experience of clinical and therapeutic follow-up. Exclusion criteria included individuals with any mental impairment, as documented in their medical records, which would prevent participation in the interview.

Data collection took place from May to October 2022, using a participant characterization form containing socioeconomic questions (age, race/ethnicity, gender, sexual orientation, marital status, education, occupation, income, housing, family composition) and in-depth interviews to explore the process of outpatient follow-up of PLHIV. The interviews were guided by the following trigger question: "Considering your HIV diagnosis and the necessary care for your health, how do you perceive your follow-up at the specialized health service?" Based on this question, subsequent inquiries aimed to investigate healthcare services more broadly, as well as other care services. For this purpose, a flexible interview script was developed, designed to address the study objective and explore other HIV-related topics that emerged during the interview.

To investigate the contexts of vulnerability among young people, Ayres' vulnerability model was adopted. This model captures the complexity and dynamics of contexts, providing a detailed view of interactions from a perspective that is limited and constantly changing. The framework facilitates the analysis of how individual, social, and programmatic factors interrelate and influence susceptibility to HIV. Although it offers a broad view, it does not aim for a complete understanding of contexts, avoiding generalizations of subjects and helping to obtain a deeper understanding of the challenges faced by young people[10].

Data collection was conducted in a private room, comprising a quiet space, free from noise and foot traffic, to allow participant reflection and comfort. The sample size was determined based on data saturation: when new topics emerged from the interviews, they were incorporated into subsequent interviews, and data collection continued until no new content was identified. The interviews were recorded in digital media, with an average duration of 40 minutes, and later transcribed in full using *Microsoft Word*®.

The research team was composed of nurses with doctoral and master's-level training in progress, with experience in this field. The transcripts were prepared by the principal investigator, and the interview material was made available to participants, although none requested it. To preserve the subjects' identities, an identification code was used, represented by the letter "J" for young person (Jovem in Portuguese) and the order of entry into the study (e.g., J01–J16).

For data operationalization, the software IRaMuTeQ® 0.7 ALFA 2.3.3.1 (acronym for *R pour les Analyses Multidimensionnelles de Textes et de Questionnaires*)[17–19] was used. Initially, a textual corpus was created from the interviews in a single Notepad file (.txt with UTF-8 encoding – all languages), which was subsequently reviewed and formatted, including standardization of acronyms and correction of language quirks, without altering the content.

Data were subjected to Descending Hierarchical Classification (DHC), in which text segments were classified through successive divisions of the material, according to the association between similar words, and then adjusted based on frequency and the Chi-Square test, forming initial classes[20]. The Chi-Square test (x^2), which allows visualization of the associations between words and the classes generated, was used to provide a graphical representation through a Dendrogram. Associations were considered significant when the Chi-Square test yielded values greater than 3.84 ($p<0.0001$)[19].

Thus, the corpus was composed of 94 text segments, with 68 segments classified, totaling 4,084 words (each equivalent to approximately 3.25 lines). Data processing was completed in 12 seconds, achieving a good efficiency rate. It is recommended that, for optimal utilization of text segments, a minimum of 75% should be classified, representing corpus homogeneity[20].

For the construction of final classes, the data processing performed by IRaMuTeQ® was combined with thematic analysis[21]. In this way, the naming of classes was based on the synthesis of expressions with the highest representativeness, resulting in two axes and five classes.

The rigor of the study was ensured through the criteria of credibility, transferability, reliability, and confirmability. Prior to data collection, the study objectives, type of participation, and average duration were clarified to the participants.

The participants were included in the study after signing the Informed Consent Form (ICF), which contained the identification of the research team, the study objectives, and the research procedures, clearly outlining the guarantees and rights related to voluntary participation, as well as the full freedom to withdraw from the study at any time, ensuring the anonymity of the information obtained. The ICF was signed by both the participant and the researcher in two copies, with each retaining one. The ethical principles established by Brazilian National Health Council Resolutions No. 466/2012 and No. 512/2016 were respected, and the research protocol was approved by the Ethics Committee of the institution involved.

RESULTS

The 16 young people who participated in the study had a mean age of 22.6 years. Regarding sociodemographic characteristics, there was a predominance of male participants (n=14), homosexuals (n=10), single individuals (n=12), those with more than eight years of schooling (n=14), self-declared whites (n=8), and those living with another family member (n=6).

Among the professions reported by the young participants, most reported having formal or informal employment, including positions such as human resources assistant, analyst, decorator, advertiser, sex worker, programmer, administrative assistant, style assistant, stock clerk, instructor, and self-employed. Additionally, two participants reported being students, and two had no employment relationship.

Approximately ten of the young participants had been living with the disease for two to six years, four had known their diagnosis for at least seven years, and two had their diagnoses revealed within the past year. Regarding medication use, twelve of the young people started Antiretroviral Therapy (ART) within less than a year after their diagnosis; three started after one year or more, and only one had not started treatment at the time of the study. Concerning the frequency of medical appointments, nine participants reported attending consultations every six months or longer, while seven had follow-up with an infectious disease physician every three to six months. Regarding the main route of transmission, sexual transmission was predominant. However, five participants reported not knowing the origin of their infection.

To understand the contexts of vulnerabilities, a summary table was created outlining the individual, social, and programmatic aspects (Figures 1 and 2), in accordance with Ayres' concepts.

Individual Contexts	
Age	Transition from adolescence to adulthood
Race/Color	Predominantly White
Gender & Sexual Orientation	Men who have sex with men (MSM)
Education Level	Generally lower
Friendship Relations	Strong
Primary Social Bonds	Friends, family, or partners
Affective/Sexual Relations	Sporadic
Social Networks & Support	School/University, church, work, health professionals (CTA*)
Drug Use	Yes (Alcohol and Marijuana)
Exposure to Unprotected Sex	Frequent
Chosen Protection for Sex	Condoms/Pre-Exposure Prophylaxis (PrEP)
Health Risk Behaviors	Frequent

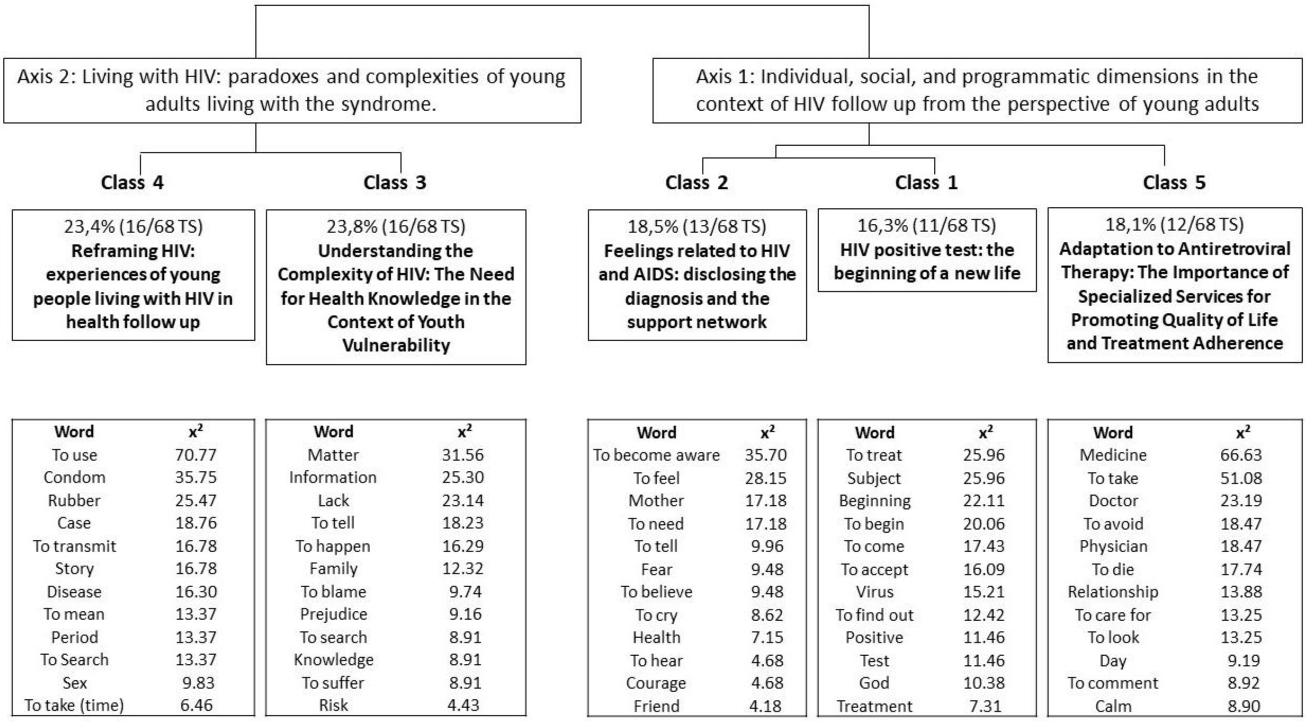
Notes: *In 2022, the period of data collection for this study, the minimum wage in Brazil was R$ 1,212.00, according to Provisional Measure 1.091/21.
Figure 1: Synthesis of individual aspects of young people living with HIV – main characteristics. Maringá, PR, Brazil, 2022.

DOI: https://doi.org/10.12957/reuerj.2025.87192

Social Contexts	
Employment	Majority with formal employment
Family Income	Predominantly 1 to 2 minimum wages*
Family Relations	Irregular
Social Behavior	Stigma and discrimination
Religion	With or without religion (most cited in that order)
Access to Sexual Education	Insufficient
Access to Leisure/Sports	Yes
Access to Digital Media	Yes
Programmatic Contexts (Health-Related)	
Coordination Between Patient Care Networks	Care primarily provided at the specialty outpatient clinic
Access to Services	Easy initial and subsequent appointments at the specialty outpatient clinic
Access to Combined Prevention Strategies	Yes
Quality of Services	Quality care from professionals; deficient physical structure; environment not very attractive to the public with HIV.
Equity in Care	Yes
Frequent Multidisciplinary Team	Doctor; nurse; social worker; psychologist
Technical-Scientific Preparation of Professionals	Yes
Respect for Privacy	Yes

Notes: *In 2022, the period of data collection for this study, the minimum wage in Brazil was R$ 1,212.00, according to Provisional Measure 1.091/21.
Figure 2: Synthesis of social, and programmatic aspects of young people living with HIV – main characteristics. Maringá, PR, Brazil, 2022.

Regarding the empirical material and the convergence of words identified through the analysis performed using the IRaMuTeQ® software, which relates the perceptions of young people between their positive HIV diagnosis and health follow-up, two axes and five interrelated classes emerged, as shown in the dendrogram presented in Figure 3.



Word	x^2
To use	70.77
Condom	35.75
Rubber	25.47
Case	18.76
To transmit	16.78
Story	16.78
Disease	16.30
To mean	13.37
Period	13.37
To Search	13.37
Sex	9.83
To take (time)	6.46

Word	x^2
Matter	31.56
Information	25.30
Lack	23.14
To tell	18.23
To happen	16.29
Family	12.32
To blame	9.74
Prejudice	9.16
To search	8.91
Knowledge	8.91
To suffer	8.91
Risk	4.43

Word	x^2
To become aware	35.70
To feel	28.15
Mother	17.18
To need	17.18
To tell	9.96
Fear	9.48
To believe	9.48
To cry	8.62
Health	7.15
To hear	4.68
Courage	4.68
Friend	4.18

Word	x^2
To treat	25.96
Subject	25.96
Beginning	22.11
To begin	20.06
To come	17.43
To accept	16.09
Virus	15.21
To find out	12.42
Positive	11.46
Test	11.46
God	10.38
Treatment	7.31

Word	x^2
Medicine	66.63
To take	51.08
Doctor	23.19
To avoid	18.47
Physician	18.47
To die	17.74
Relationship	13.88
To care for	13.25
To look	13.25
Day	9.19
To comment	8.92
Calm	8.90

Notes: *x^2: chi-square; ST: text segments
Figure 3: Descending Hierarchical Classification Dendrogram produced by IRaMuTeQ® software regarding the perceptions and outpatient follow-up of young people living with HIV. Maringá, PR, Brazil, 2022.

DOI: https://doi.org/10.12957/reuerj.2025.87192

The first axis, which is the central theme of the present study, refers to the experiences in the process of discovery, acceptance, and health follow-up, encompassing classes 1 (individual dimension), 2 (social dimension), and 5 (programmatic dimension). The second axis, in turn, portrays the ambivalence of feelings regarding the complexity of HIV and AIDS, grouping classes 3 and 4.

Axis 1: Individual, social, and programmatic dimensions in the context of HIV care from the perspective of young adults

HIV Positive Test: The Beginning of a New Life

Class 1 represented 16.3% of the text segments, showing a strong connection between the words *treat*, *issue*, and *start/begin*. The terms highlighted in this class referred to the process of users entering the service, starting from the test and the confirmation of a positive HIV serology. There was a clear relationship among the words *virus*, *discover*, *accept*, *test*, *positive*, and *treatment*, denoting the importance of the service for the continuity of health care, under a multidisciplinary and supportive approach to help the young person face and understand their health condition.

> *"My first test came back positive, and I found out that there was a specific program for the treatment of sexually transmitted diseases. There is also psychological support, which is really good." (J7)*
>
> *"I had had some relationships and didn't use a condom in some of them, so I thought it was important to get tested and be more careful from then on, because I realized I had messed up." (J8)*
>
> *"The hospital referred me; they gave me the protocol and my mother accompanied me. Honestly, I didn't even know about it. When I arrived here, I received social assistance, which talked to me and my mother and explained everything properly." (J12)*

Feelings Related to HIV and AIDS: Disclosing the Diagnosis and the Support Network

Class 2 represented 18.5% of the text segments, with the most relevant words being *know*, *stay*, *mother*, and *need*. These terms reflect individuals' experiences following an HIV diagnosis, particularly the emotional impact of learning their serology results and how this relates to sharing the information with family members or previous partners. The word *fear* may be associated with concern about stigma and prejudice, as well as uncertainties regarding the consequences of the disease, which can affect the individual's chances of survival. The need for support and the emotions experienced are evident in this class, along with shock and crying related to health (loss).

> *"[...] it made me very afraid of dying. Really scared, so I think it did contribute in a positive way, I would say, because I didn't die, I'm still here." (J6)*

The search for care, when facing suspected HIV infection, involves health issues and established social patterns. As such, the reports highlight the importance of maintaining confidentiality regarding the diagnosis. Disclosing the diagnosis was an important, though sometimes ambiguous, factor noted by participants.

> *"At first, it was my mother who suggested I get tested. From there, we started the treatment. At that time, I received treatment at a CTA in another city to avoid the 'gossip,' because it was a small town, and back then I had an enormous stigma about HIV." (J7)*

The health service, as a support network, provides safety and confidence to the patient. Developing a closer relationship between the patient and the healthcare professional and maintaining a bond of trust strengthens the connection, ensuring continuity and adherence to treatment.

> *"[...] Also, it was the words they exchanged with me, especially the nurse who made my first diagnosis, he said everything would be fine, that I would have a normal life. The nurse and the nursing staff said this, which comforted me a lot." (J8)*
>
> *"So for me it's amazing, it's really amazing to know that there is free treatment, psychological support if needed, and that you have all your tests up to date(...)" (J7)*

Adaptation to Antiretroviral Therapy: The Importance of Specialized Services for Promoting Quality of Life and Treatment Adherence

Class 5, which represented 18.1% of the text segments, focused on the process of adherence and adaptation to medication, as well as the clinical follow-up of people living with HIV (PLHIV). The words *medication*, *take*, and *doctor* were strongly associated, indicating that health services are essential for improving access to care, as well as restoring belief in the possibility of a normal and quality life.

DOI: https://doi.org/10.12957/reuerj.2025.87192

> *"He tells me that if I want to get pregnant and if my partner does not have HIV, is not a carrier, my child won't be affected because this medication I take is designed so I can get pregnant without transmitting it to my baby." (J1)*

> *"I thought it would be a bit difficult, regarding taking the medication and all that, but it's actually quite manageable. It's medication for life, there's no choice, so I just have to adapt." (J11)*

Axis 2: Living with HIV: Paradoxes and Complexities of Young Adults with the Syndrome

Understanding the Complexity of HIV: The Need for Health Knowledge in the Context of Youth Vulnerability

In Class 3, the text segments represented 23.8% of the total corpus analyzed. In this class, there was a strong association with the words *issue*, *information*, and *lack (of information)*, which reflected gaps in sexual and health education reported by the young participants. It was observed that health services play a fundamental role in welcoming people living with the disease, especially through actions aimed at guiding and supporting individuals in this new health scenario.

> *"[...] I also had questions, and they answered them well, because we have doubts. In the beginning, we don't have knowledge; I believe they were very patient with me." (J1)*

The acts of *telling* and *talking* demonstrate that guidance actions are essential in the work of professionals for young people who need information to understand their condition, thereby strengthening self-care.

> *"The doctor is very helpful, she's always on my case, you know? And a service like this is very good." (J12)*

Experiencing, suffering, and *feeling guilty* about HIV infection are very present in the lives of young people; however, these perceptions can be mitigated by health professionals.

> *"All the professionals involved bring this affective, very empathetic aspect; I felt very embraced, very supported through this whole situation. The health professionals at the CTA deserve congratulations for the entire process, for all the care. It's important for a patient's life because it is here that the patient ends up being welcomed and heard. Unfortunately, outside of here, in society, we don't have that possibility." (J14)*

Reframing HIV: Experiences of Young People Living with HIV in Health Follow-up

Class 4, which represented 23.4% of the text segments, reflected on the participants' own actions related to *transmitting HIV, using condoms*, *engaging in (safe or unsafe) sex*, and adopting self-care measures, based on the guidance provided by the service.

> *"[...] my health has improved, I was extremely debilitated and I can't explain it, but I wouldn't say it's a welcoming environment like: wow, I can't wait to come here!" (J6)*

> *"For me, the CTA is incredible, it's really amazing to know that there is free treatment, psychological follow-up if necessary, you have all the exams up to date. Today I really take care of myself, and the CTA is behind all of this." (J7)*

Follow-up at the specialized service, in addition to providing comfort, gives the young person the knowledge necessary to live with the disease, offering information that should be adopted to prevent HIV infection and to care for others, meaning providing protection to their partners in relationships.

Everyday experiences in HIV follow-up, related to care at the outpatient clinic—referred to by participants as the Testing and Counseling Center (CTA)— described here as *delays* (in service), *waiting periods* (at the facilities), and the *history* and *social meaning* (of the disease in society), convey to the young person a sense of exposure of their condition to the observation of other patients circulating in the clinic. This situation is perceived as uncomfortable and potentially disruptive to continuity of care.

> *"[...] it's kind of annoying in that sense because they could keep everything separate in the hospitals, like it used to be, because you go there, the person doesn't know what you're being treated for.. Here you arrive, and the next day it's all over town, 'oh, they were at the CTA,' and whether you like it or not, the clinic is known as the HIV hospital." (J5)*

> *"[...] but I wouldn't say it's a welcoming environment like, 'oh, I can't wait to come here.' Maybe if it were more private, more anonymous, it would be a little more comfortable." (J6)*

DISCUSSION

It is evident that young people living with HIV face a wide range of vulnerabilities, whether individual, social, and/or programmatic. The concept of vulnerability primarily refers to susceptibility to harm[8]; however, it is also necessary to understand the broader situations surrounding the disease, including the contexts of health follow-up.

Ayres highlights that the three axes that constitute vulnerability are related to specific aspects of an individual's life. Regarding young people living with HIV, they are particularly susceptible to certain risk situations inherent to this stage of life[10,11].

Thus, this study analyzes young people's perspectives on HIV from the moment of a positive diagnosis, which determines their health follow-up. However, the process of discovering an HIV diagnosis is often associated with feelings of sadness and disappointment, since this health condition is socially stigmatizing and represents a significant challenge for people living with HIV (PLHIV)[23,24].

Furthermore, many young people do not always recognize their own health needs. Through their narratives, indifference toward the new diagnosis is observed, which cannot be separated from the routine way HIV is perceived in people's daily lives[25].

Furthermore, discovering a positive HIV diagnosis often generates uncertainties regarding future prospects, representing a turning point in the individual's life. This affects not only the way they relate to society, especially friends and family, but also the daily need for therapeutic care. This new phase can lead to negative feelings such as fear, shame, sadness, and loss, which may contribute to social isolation[25].

A study conducted in Rio de Janeiro, Brazil, found that people living with HIV in the early stages of treatment often have a negative perception of their diagnosis, associating their health condition with a death sentence[26].

The paradoxical feelings between the need to disclose the diagnosis and the desire to maintain confidentiality with family members, partners, or even healthcare professionals create emotional and social repercussions that impact the lives of people living with HIV. Thus, while the family nucleus is considered the first social and community institution and can serve as a support network for coping with the disease, it can also reinforce social stigmas, leading to exclusion and stress for individuals[27].

Regarding healthcare professionals, framing HIV as a chronic condition like any other can help minimize the stigmatizing effects associated with the perception of infected individuals as weak and the fear of imminent death. This approach promotes a shift in life perspective and acceptance of the positive diagnosis[26].

Even when young people reinterpret their way of living with HIV and have the support of healthcare services, they still face everyday challenges, such as delays in care, waiting for consultations, and obtaining medications.

Considering the stigma and prejudice imposed by society on people living with HIV (PLHIV), it becomes necessary for healthcare professionals to adopt a welcoming attitude toward these individuals and to establish a strong connection with young patients, employing health strategies aimed at maintaining adherence to treatment.

A study conducted in Boston showed that psychosocial interventions with young people have the potential to improve overall health outcomes and reduce cases of AIDS[28]. Thus, psychosocial interventions can serve as a strategy to minimize waiting times for care and to facilitate accessibility, reduce inequalities, and overcome structural and institutional barriers to treatment continuity[28].

In addition to possible interventions in care delivery, there is a highlighted need for qualified listening within a framework of confidentiality, allowing individuals to trust healthcare professionals and communicate their doubts, desires, experiences, and exposure to risks. Concurrently, scientific evidence supports the empowerment of PLHIV through the construction of reliable knowledge about the repercussions of HIV, enabling a re-signification of their own life perception and the adoption of healthy habits[28].

Regarding treatment, upon being diagnosed with HIV, young people experience a range of emotions and reinterpret their new experiences during follow-up, including adapting to medication. This stage, according to the participants' perception in the study, has been positive in terms of the possibility of having a life like other people who do not have HIV. Nevertheless, HIV, as a significant life experience, has led to transformations in personal habits, such as increased mental and physical self-care following the diagnosis[25].

In this perspective, clinical monitoring of these young people is a fundamental strategy for healthcare follow-up and for improving access to treatment, especially considering the advances in public policies aimed at care and treatment of the disease over the years for young people, who are considered a vulnerable group for HIV infection[4].

Difficulties in implementing sexual education by healthcare professionals can impact the lives of young people living with HIV, who may experience feelings of guilt and suffering that can persist throughout life, making living with HIV complex if there is no support from the healthcare network[29-30].

Understanding the complexity surrounding HIV reveals inherent gaps in the sexual education process for young people, which can directly influence the adoption of behaviors harmful to health and lead to exposure to HIV and other STIs. The paradigms associated with the concepts of sexuality and sexual education are linked to the environment in which individuals are inserted, within a specific historical and social context[29,30].

These difficulties regarding sexual education affect young people in many parts of the world. A study conducted with this population in Southeast Asia identified the need to implement programs to promote communication between parents and adolescents about sex and HIV during adolescence, train teachers for HIV awareness, and develop peer-led education programs led by young people and LGBTQIAPN+ populations (Lesbian, Gay, Bisexual, Trans, Queer/Questioning, Intersex, Asexual/Aromantic/Agender, Pan/Poly, Non-binary), with the aim of promoting HIV prevention, sexual and mental health, resilience, and empowerment, consequently transforming political and sociocultural contexts[31].

Moreover, follow-up in specialized services also provides young people with multiprofessional care that can help mitigate gaps in sexual knowledge, enhancing the understanding of sexuality, sexual relationships after an HIV diagnosis, and the adoption of preventive methods to protect the health of their partners[26].

Study Limitations

Regarding the limitations of this study, the interpretation should be approached with caution, as the findings reflect the experiences of a specific group of young people living with HIV who receive follow-up care in a particular outpatient clinic but reside in different municipalities with diverse populations. These differences may influence their social interactions, the healthcare networks they are part of, and possible variations in the approach of healthcare professionals at other stages of care.

FINAL CONSIDERATIONS

The perceptions of young people living with HIV regarding healthcare follow-up reveal that they are inserted in dynamic, subjective, and complex contexts, influenced by vulnerability factors that negatively affect their youth, social relationships, and health. The results of this study were organized into five thematic classes encompassing individual, social, and programmatic aspects, reflecting the vulnerabilities and unique experiences of these young people. Throughout their pursuit of care, the importance of healthcare services is highlighted—from diagnosis, through the initiation of antiretroviral therapy, to ongoing follow-up.

Unfortunately, discrimination continues to permeate the lives of these young people, extending the stigma experienced at the time of HIV diagnosis and persisting to the present moment. This underscores the importance of sexual and health education as a key factor in health promotion and disease prevention, serving also as a mechanism to clarify and minimize the effects of stigma.

In this context, health prevention emerges as necessary, urgent, and mandatory, as adolescents and young adults are more susceptible to psychosocial suffering, which can lead to mental health issues. Therefore, it is suggested that healthcare professionals focus on their practice, especially on preventing health harms in young populations, ensuring the provision of adequate knowledge to promote cognitive and behavioral change, thereby contributing to the prevention of HIV and other diseases.

REFERENCES

1. Arantes. LMN, Pedroso AO, Menegueti MG, Gir E, Botelho EP, Silva ACOE, et al. factors associated with late diagnosis of Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome (HIV/AIDS) in a university hospital in Brazil: challenges to achieving the 2030 target. Viruses. 2023 [cited 2024 mar 15]; 15(10):2097. DOI: https://doi.org/10.3390/v15102097.
2. UNAIDS. O caminho que põe fim à AIDS: Relatório Global do UNAIDS 2023. Genebra: Programa Conjunto das Nações Unidas sobre HIV/AIDS; 2023 [cited 2024 feb 02]. Available from: https://brasil.un.org/sites/default/files/2023-07/JC3082_GAU2023-ExecSumm_v2_embargoed_PT_VF_Revisada-EA.pdf.
3. Ministério da Saúde (Br). Secretaria de Vigilância em Saúde. Departamento de Vigilância, Prevenção e Controle das Infecções Sexualmente Transmissíveis, do HIV/Aids e das Hepatites Virais. Boletim Epidemiológico HIV/AIDS. Brasília (DF): Ministério da Saúde; 2023 [cited 2024 feb 02]. Available from: https://www.gov.br/Aids/pt-br/central-de-conteudo/boletins-epidemiologicos/2023/hiv-Aids/boletim-epidemiologico-hiv-e-Aids-2023.pdf/view.
4. Ministério da Saúde (Br). Sexualmente Transmissíveis, do HIV/Aids e das Hepatites Virais. Boletim Epidemiológico HIV/AIDS. Brasília (DF): Ministério da Saúde; 2024 [cited 2025 sep 07]. Available from: https://www.gov.br/Aids/pt-br/central-de-conteudo/boletins-epidemiologicos/2024/boletim_hiv_Aids_2024e.pdf/@@download/file.
5. Olinover M, Hamama L. Adolescents during wartime: Vulnerability-based profiles. J Res Adolesc. 2025 [cited 2025 sep 08]; 35(2):e70041. DOI: https://doi.org/10.1111/jora.70041.
6. Cruz MLS, Darmont MQR, Monteiro, SS. HIV-related stigma among young people living with HIV transitioning to an adult clinic in a public hospital in Rio de Janeiro, Brazil. Cien Saúde Colet 2021 [cited 2024 feb 21]; 26(07):2653-62. DOI: https://doi.org/10.1590/1413-81232021267.07422021.
7. Ministério da Saúde (Br). Secretaria de Vigilância em Saúde. Aids / HIV. Brasília (DF): Ministério da Saúde; 2025 [cited 2025 sep 08]. Available from: https://www.gov.br/saude/pt-br/assuntos/saude-de-a-a-z/a/Aids-hiv.

8. Ayres JRCM, Calazans GJ, Filho HCS, França Júnior IF. Risco, vulnerabilidade e práticas de prevenção e promoção da saúde. In: Campos GWS, Minayo MCS, Akerman M, Drumond Júnior M, Carvalho YM. Tratado de saúde coletiva. Rio de Janeiro: Hucitec; 2006. p. 354-95.
9. Mann J, Tarantola DJM. AIDS in the world. New York: Oxford University Press; 1996.
10. Ayres JR. Vulnerability, Care, and integrality: conceptual reconstructions and current challenges for HIV/AIDS care policies and practices. Saúde Debate. 2022 [cited 2024 mar 03]; 46:196–206. DOI: https://doi.org/10.1590/0103-11042022E714.
11. Ayres JR. Vulnerabilidade, direitos humanos e cuidado: aportes conceituais. *In*: Barros S, Campos PFS, Fernandes JJS. Atenção à saúde de populações vulneráveis. Barueri: Manole; 2014.
12. Fernandes I, Bruns MAT. Systematic review of the national scientific literature about the history of HIV/Aids. Rev Bras Sex Hum. 2021 [cited 2024 mar 05]; 32(1):60-5. DOI: https://doi.org/10.35919/rbsh.v32i1.916.
13. Matos VC, Torres TS, Luz PM. Adherence to antiretroviral therapy among cisgender gay, bisexual and other men who have sex with men in Brazil: evaluating the role of HIV-related stigma dimensions. PLoS ONE. 2024 [cited 2025 sep 07]; 19(8):e0308443. DOI: https://doi.org/10.1371/journal.pone.0308443.
14. Fauk NK, Hawke K, Mwanri L, Ward PR. Stigma and discrimination towards people living with HIV in the context of families, communities, and healthcare settings: a qualitative study in Indonesia. Int J Environ Res Public Health. 2021 [cited 2024 mar 04]; 18(10):5424. DOI: https://doi.org/10.3390/ijerph18105424.
15. Minayo MCS, Costa AP. Fundamentos Teóricos das técnicas de investigação qualitativa. RLE. 2018 [cited 2024 feb 15]; 40:139-53. Available from: https://revistas.ulusofona.pt/index.php/rleducacao/article/view/6439.
16. Altman DG, Simera I, Hoey J, Moher D, Schulz K. EQUATOR: reporting guidelines for health research. Lancet. 2008 [cited 2024 feb 15]; 371(9619):1149–50. DOI: https://doi.org/10.1016/s0140-6736(08)60505-x.
17. Ratinaud P. IRAMUTEQ®: Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires - 0.7 alpha 2 [Site de Internet]. 2014 [cited 2024 jan 29]. Available from: http://www.IRAMUTEQ®.org.
18. Sousa YSO, Gondim SMG, Carias IA, Batista JS Machado DCM. The use of the IRAMUTEQ® software in the interview data analysis. Pesqui. prát. Psicossociais. 2020 [cited 2024 mar 04]; 15(2):e3283. Available from: http://pepsic.bvsalud.org/pdf/ppp/v15n2/15.pdf.
19. Souza MAR, Wall ML, Thuler ACMC, Lowen, IMV, Peres AM. The use of IRAMUTEQ® software for data analysis in qualitative research. Rev Esc Enferm USP. 2018 [cited 2024 mar 04]; 52:e03353. DOI: https://doi.org/10.1590/S1980-220X2017015003353.
20. Camargo BV, Justo AM. Tutorial para uso do software IRAMUTEQ® (Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires). Florianópolis (SC): Universidade Federal de Santa Catarina; 2021.
21. Bardin, L. Análise de conteúdo. São Paulo, SP: Edições 70, 2016.
22. Garcia EC, Costa IR, Oliveira RC, Silva CRL, Góis ARS, Abrão FMS. Social representations of adolescents about HIV/AIDS transmission in sexual relations: vulnerabilities and risks. Esc Anna Nery. 2022 [cited 2024 may 01];2 6:e20210083. DOI: https://doi.org/10.1590/2177-9465-EAN-2021-0083.
23. Pimentel GS, Ceccato MGB, Costa JO, Mendes JC, Bonolo PF, Silveira MR. Quality of life in individuals initiating antiretroviral therapy: a cohort study. Rev Saúde Pública 2020 [cited 2024 may 03]; 54:146. DOI: https://doi.org/10.11606/s1518-8787.2020054001920.
24. Du X, Zhang Q, Hao J, Gong X, Liu J, Chen J. Global trends in depression among patients living with HIV: a bibliometric analysis. Front Psychol. 2023 [cited 2024 may 03]; 14:1125300. DOI: https://doi.org/10.3389/fpsyg.2023.1125300.
25. Sanca AM, Motta MGC, Giugliani C, Rocha CMF, Riquinho DL. The daily life of people living with HIV in Bissau, Guinea-Bissau: perspectives, challenges and vulnerabilities. Esc Anna Nery 2023 [cited 2024 May 03]; 27:e20210507. DOI: https://doi.org/10.1590/2177-9465-EAN-2021-0507pt.
26. Muniz CG, Brito C. What does the diagnosis of HIV/AIDS represent after four decades of epidemic? Saúde debate. 2022 [cited 2024 may 05]; 46(135):1093–106. DOI: https://doi.org/10.1590/0103-1104202213510.
27. Ninnoni JP, Nsatimba F, Agyemang SO, Commey IT, Bennin L, Agyare E, et al. An exploratory qualitative study of the psychological effects of HIV diagnosis; the need for early involvement of mental health professionals to improve linkage to care. BMC Public Health 2023 [cited 2025 sep 08]; 23:2518. https://doi.org/10.1186/s12889-023-17449-y.
28. Whiteley LB, Olsen EM, Haubrick KK, Odoom E, Tarantino N, Brown LK. A review of interventions to enhance HIV medication adherence. Curr HIV/AIDS Rep. 2021 [cited 2024 jun 10]; 18(5):443-57. DOI: https://doi.org/10.1007/s11904-021-00573-y.
29. Diura-Vere O, Mokgatle MM, Oguntibeju OO. Sexual behaviour and attitudes towards safe sex of youth receiving antiretroviral care at public health facilities in Palapye District, Botswana. Int J Environ Res Public Health. 2023 [cited 2024 may 20]; 20(5):3790. DOI: https://doi.org/10.3390/ijerph20053790.
30. Duarte-Anselmi G, Leiva-Pinto E, Vanegas-López J, Thomas-Lange J Experiences and perceptions on sexuality, risk and STI/HIV prevention campaigns by university students. Designing a digital intervention. Ciênc saúde coletiva. 2022 [cited 2024 may 20]; 27(3):909–20. DOI: https://doi.org/10.1590/1413-81232022273.05372021.
31. Newman PA, Prabhu SM, Akkakanjanasupar P, Tepjan S. HIV and mental health among young people in low-resource contexts in Southeast Asia: a qualitative investigation. Glob Public Health. 2022 [cited 2024 may 20]; 17(7):1200-14. DOI: https://doi.org/10.1080/17441692.2021.1924822.

Authors contributions

Conceptualization, B.S.F. and M.F.G.L.M.; methodology, B.S.F. and M.F.G.L.M.; validation, B.S.F., T.F.C.S.R. and M.F.G.L.M.; formal analysis, B.S.F., T.F.C.S.R. and M.F.G.L.M.; investigation, B.S.F., T.F.C.S.R. and M.F.G.L.M.; data curation, B.S.F., T.F.C.S.R. and M.F.G.L.M.; manuscript writing, B.S.F., T.F.C.S.R., C.M.G.P., G.M.S., L.A.S., R.A.P., M.D.F. and M.F.G.L.M.; review and editing, B.S.F., T.F.C.S.R., C.M.G.P., G.M.S., L.A.S.,

R.A.P., M.D.F. and M.F.G.L.M.; visualization, B.S.F., T.F.C.S.R., C.M.G.P., G.M.S., L.A.S., R.A.P., M.D.F. and M.F.G.L.M.; supervision, B.S.F., T.F.C.S.R., C.M.G.P., G.M.S., L.A.S., R.A.P., M.D.F. and M.F.G.L.M.; project administration, B.S.F. and M.F.G.L.M.; financing acquisition, B.S.F. and M.F.G.L.M. All authors read and agreed with the published version of the manuscript.

Use of artificial intelligence tools

Authors declare that no artificial intelligence tools were used in the composition of the manuscript "*Young people living with HIV: perceptions of healthcare follow-up in light of vulnerability concepts*".