

Trajectories of adolescents living with vertical transmission-HIV virus

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THEMATIC ARTICLE

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Abstract *This study analyzes the life stories of eight young people living with vertically transmitted HIV in order to understand their perceptions marked by secrecy and silence regarding their experiences with the virus. Conducted at a specialized outpatient clinic in Rio de Janeiro, the study adopted circle dance, a Complementary and Integrative Health Practice, as a care tool. Using a qualitative approach and Life History as a data collection method, the focus was to understand the youth's experiences related to the disease and the crucial aspects of their lives. Three girls and five boys participated in the study, all aware of their diagnosis. The principal emerging themes included family dynamics, school environment connection, challenges in treatment adherence, age at the time of diagnosis disclosure, and time elapsed since then. Analyzing these young people's narratives allowed us to explore individual and social aspects of their experiences, revealing their similarities and differences. The circle dance workshops provided a playful space for expressing emotions and feelings through body movements, expanding young people's perspectives on the future.*

Key words *HIV, Vertical Transmission of Infectious Disease, Adolescent Health, Life History, Complementary Therapies*

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Introduction

This article addresses the construction and analysis of the life stories of eight young people being monitored at the Pediatric Infectious Diseases Outpatient Clinic (DIPe) of a high-complexity public hospital, a reference for caring for children and adolescents in Rio de Janeiro. It focuses on the care of young people living with vertical-transmission HIV, exploring the complexities following diagnosis. We aim to understand how these young people narrate their experiences of living with HIV, which are often marked by secrecy and silence. Moreover, we seek to cover different social stakeholders and aspects of their lives.

Adolescence is marked by significant bodily, psychological, emotional, and social changes. According to the WHO¹, it is chronologically confined to the second decade of life, from 10 to 19 years. From a socio-historical perspective, adolescence emerges as a concept and social category. Thus, it is not just a period of preparation for adult life². Ozella³ affirms that the idea of adolescence as a naturalized, universalized, pathologized, and stereotyped phase is being overcome. The author argues that this is a period of human development resulting from social and historical construction and individual features.

Thus, being aware of HIV status at this life stage, which in itself is permeated by changes, discoveries, the search for autonomy, and marked by developing sexuality, is a considerable challenge. It requires these young people to manage a highly stigmatized chronic condition, which adds to the whirlwind of age-specific transformations.

Studies conducted in sub-Saharan African countries^{4,5} reveal a challenging setting for adolescents living with HIV compared to their peers in the same age group who do not face chronic diseases. They often face economic, social, and psychological difficulties, which, in turn, affect their outlook on life, resulting in repressed aspirations and sometimes feelings of failure, depression, suicidal ideas, and self-mutilating behavior. This situation becomes even more complex for those who face socioeconomic problems, educational hardship, or belong to socially vulnerable families⁶. These issues are compounded by the stigma and discrimination associated with HIV.

In Brazil⁷ and Uruguay⁸, authors point to a culture of silence that prevails regarding issues related to HIV and sexual and reproductive health. Adolescents are often conditioned to adopt it as the only plausible strategy to avoid exclusion and

stigma. This behavior, however, deprives them of access to information and support that would do them so much good.

It is, therefore, important that professionals caring for these adolescents understand and address the complex interactions between HIV, socioeconomic inequalities and the stigma surrounding this disease, ensuring fair opportunities to thrive, overcome obstacles, and empower themselves in managing their health and building a promising future. Why not?

The excerpts from the stories told here should be understood because they contain successful experiences, difficulties, dreams, and expectations that need to be heard. Circle dance-mediated conversations created a mosaic that, while not universally representative, includes all the young people treated at this hospital.

Methods

This qualitative study was based on the Life Story method. Data collection involved multiple strategies to immerse young people in their experiences at different stages and contexts. The central objective was to gain a deeper understanding of their experiences, considering their perspectives, the influences of social stakeholders, and the daily dynamics that permeate their lives.

Thus, participant observations occurred during medical appointments from December 2022 to June 2023, with the permission of professionals, adolescents, and their guardians, besides exploring the medical records of each young person and conversation circles mediated by circle dance.

The circle dance intervention was chosen for eight young people to promote interaction and communication during eight sessions. Considered an Integrative and Complementary Health Practice (PICS), this type of dance is a bodily expression inspired by traditional cultures, which uses the group circle to promote physical, mental, emotional, and social well-being. Freire and Minayo⁹ emphasize that this practice favors meaningful interactions with external reality and facilitates the resignification of aspects of life in the face of challenges, encouraging a creative experience and providing participants with care that exceeds what is prescribed.

The circle dance-mediated intervention occurred on previously scheduled days and lasted one hour. In the end, the conversation was motivated by the triggering question, "What was it

like for you to take part in this activity?” followed by questions to deepen the listening experience of these young people about being an adolescent and living with HIV, the main challenges, and what they think and know about their health condition. The conversations were recorded and transcribed.

During the clinical visits, the family dynamics linked to healthcare due to HIV were observed to understand the care trajectory of these adolescents and their interaction with health services. These observations were recorded in a field diary and supplemented by information from the medical records of the multi-professional health team. A roadmap was employed to collect information from the medical records, covering the young people’s medical and treatment history, besides clues as to how the secret surrounding the diagnosis was revealed. These elements broadened our understanding of each participant’s therapeutic trajectory and life story.

The stories described here summarize what was woven into the meetings between the researcher and the participants. The analysis of the material was based on the phenomenological perspective proposed by Schutz¹⁰, which seeks to highlight the most relevant meaning attributed by the social stakeholders participating in the research to their experiences. We aimed to understand how these young people describe their experiences of living with HIV, producing meanings shared in specific contexts. The analysis sought to highlight the development of a personal trajectory shared collectively and part of a broader social context.

We considered that, within narrative theories¹¹⁻¹⁵, the “life story” method would be the most appropriate strategy for presenting the expected results, which is justified because people explain how they experience their humanity¹⁶ by telling their story.

Life stories are a powerful approach to understanding socialization processes and personal and group experiences since narrating facilitates discovery, exploration, evaluation, and interpretation, although, as Gadamer¹⁷ reminds us after Heidegger¹⁸, no one can tell the truth, but rather their vision of the experience of the facts, based on their life script¹⁹⁻²¹.

The researcher must be careful when using this approach: (1) Not acting as a guide, but as a facilitator. Although interacting with the research subject is permeated by power relationships, it tends to release the narrator’s ability to tell and interpret when it happens appropriately. (2) Building a relationship of trust and respect.

It is not up to the interviewer to say whether something is true or false or imagination or reality. People should build a reflective environment in which questions and (minimal) interventions are only intended to deepen what is being said. (3) Ensuring the confidentiality of disclosures. In this study, this was done by allowing the participants to choose the name with which they would like to be identified.

Reflecting on the facts and experiences narrated directed the research toward the crucial aspects of the lives of these young people with HIV and their consequences. However, the focus was not on the disease but on understanding their experiences.

The participants and their guardians signed the Informed Consent Form and the Informed Assent Form on behalf of the adolescents. The requirements of Resolution No. 510 of April 7, 2016, which regulates research in the humanities and social sciences, were complied with and approved by the Institutional Research Ethics Committee under No. Opinion 5.590.092.

Results

Among the most important themes that emerged from this study were family dynamics, including the figure of the primary caregiver and adoptions, the connection with the school environment, the challenges in adhering to treatment, the age of the young people when the diagnosis was revealed, and the time elapsed since this crucial moment.

Three girls aged 14-17 and five boys aged 12-17 participated in the study. All were aware of their HIV diagnosis. The accounts below highlight a specific phase in the personal journey of this group of adolescents, shaped by the influence of the life stories of their parents or guardians. The narratives emphasize the ways of being and acting, the characters, and the environments that underlie the scenario of their lives.

Stories of young people living with HIV

1 - “Laughing is an act of resistance”. Is what this 14-year-old Black girl who participated in the circle dance workshops wanted to be called. She has a twin brother, both adopted by a couple when they were just over a year old. While her brother is not an HIV carrier, “Laughing is an act of resistance” began her follow-up at the clinic before she was a year old, showing assiduity at

her appointments and tests. This adolescent has no difficulty taking her medication. She names them “HIV drugs”. She knows the timetable and has some autonomy. *“The HIV medication I take without my mother having to talk to me, but my mother has to talk to me about Dr. [psychiatrist]’s medication.”* The conversation about her diagnosis was integrated into the narrative of her adoption, like a thread that runs through her story.

“Laughing is an act of resistance” is always accompanied by her mother during medical appointments, as her father is not very present at these times, in her own words. She reveals a shy and introverted personality. She does well at school, gets good grades, and enjoys friendships. At the age of 12, she began to go to her appointments independently, initially limiting herself to answering the questions asked by the health team. However, she began to share more over time, revealing aspects of her life, asking questions, and confiding secrets, gradually showing her trust in the person attending her. Her shyness gave way to many smiles. Sometimes, at the end of the appointment, her mother would express some concern, especially about *“Laughing is an act of resistance”* behavior, which was accepted and discussed by the team in the presence of mother and daughter to mediate this relationship.

The invitation to participate in the research was received enthusiastically, representing an opening to express their experiences and emotions. *“I liked this circle dance activity. I thought it was fun, calm, nice, and calm”*.

2 - “2006”. Is what he chose to call himself. “2006” is a 16-year-old boy, born in the same hospital where he is treated to this day, a few weeks earlier than expected, at 33 weeks gestation. He has been followed up in the outpatient clinic ever since. “2006” is brown and bears traces of another ethnicity in his appearance, inherited from a father he never knew. The biological mother of “2006” was already in foster care. His deceased father was never involved in caring for his son. His grandmother took on the maternal role after his biological mother’s death. She is the one he refers to today as his mother.

From an early age, “2006” learned to walk the path of independence. He manages his medication and is primarily responsible for his appointments, tests, and all aspects of his life. He knows the medicines’ names and can take them without his mother’s help: *“I take the medicines myself. Bivior, lamivudine, and another one I’ve forgotten the name of. One is bad and tastes like water with lemon”*.

He struggles at school, a journey marked by challenges: *“There’s no salvation at school. There’s always a fight. In the last one, I was expelled because I hit the boy with a chair, and he dislocated his leg. Everyone was angry at me, but he broke my tablet”*. He describes himself as someone prone to nervousness, often overwhelmed by irritation in everyday interactions. *“I have to learn to relax”*.

His exact recollection of when he became aware of his diagnosis is vague, but “2006” estimates that it happened around the age of 10. *“I found out when I was older, and I’ve had it since I was born. I knew I had a health problem, but I didn’t know what it was”*. He is tireless in keeping up to date with advances in treatment and research into finding a cure for HIV. Outspoken and articulate, he likes to share his opinions and interact warmly in the group. Adherence to the research was immediate, as “2006” wanted to contribute by actively participating in the proposed activities. *“I liked this activity; it’s exciting, and I felt calm. I got up early, I’m sleepy, but now I’m happy; I came out of this activity refreshed”*. In one of the workshops, “2006” suggested an activity she had learned in the theater, showing creativity and involvement with the group and the research.

3 - “Ocean” was the name chosen by a young woman full of conviction, expressive, and unafraid to express her thoughts. While initially reserved, she often seemed bored at appointments, *“I only have 1% love, and the rest is all anger. I’m 1% affectionate when I want to be. I was born that way, without patience”*, it was enough to interact with something that aroused her genuine interest and to be asked about her worldview for her to shed her first impressions, gaining confidence for a frank conversation.

In the research, “Ocean” self-declared white. About turning 18, the young woman was being transferred to the adult service, marking a significant transition in her medical care.

Difficulties and challenges mark her relationship with her mother. *“I can’t talk about my feelings. I’m afraid of my mother”*. Her mother conceived her very young, relying on her grandmother to raise her. Her father was not involved and is deceased. During Ocean’s childhood, her grandmother played the maternal role and indulged her every wish, pampering her excessively. In her teens, her mother took over the care of her daughter, remarried, and had a son who did not carry HIV.

Ocean’s adherence to medication is a daily struggle. She faces considerable challenges, as

she feels unable to manage the medication on her own: *"I don't take the medication myself. My mother still gives it to me, and she complains a lot. To this day, I can't take it myself. I'm going to, but I haven't worked up the courage"*.

The medication serves as a constant reminder of her condition, an anchor that pulls her back to the reality of the virus. "Ocean" faces swings in her adherence to treatment, with periods of detectable viral load due to medication administration failures, which result in adverse consequences for her health, experiencing the consequences of treatment failures in her body. The mother feels and expresses the difficulties of dealing with her daughter's personality and temper.

Since birth, "Ocean" has been monitored by the outpatient clinic at the same hospital where the research was conducted. The revelation of her diagnosis, which came at the age of 12, was a lengthy process permeated by persistent questions about the need for medication. Confirmation occurred in the school environment with the help of two education professionals. The young woman says she likes going to school. *"School is sometimes quieter than home"*. Although she has already repeated the year, she strives to get good grades. She has friends and, recently, a boyfriend.

At first, "Ocean" expressed skepticism and fear about the research, raising questions and setting conditions. However, she participated actively in the proposed activities, offering suggestions for the next ones and highlighting her passion for dance. *"I like dancing. Doing an activity like this here in the hospital is very good"*. She once asked for her school's samba to be played on the loudspeaker. A moment of celebration. This wish was granted, reinforcing the importance of expression during the activities. So, the wheel turned to the sound of the chosen melody.

4 - "Rimuru", as he wanted to be called, began his follow-up at the clinic at the age of seven. His mother underwent a test that confirmed her HIV infection. In a new chapter of her life, she remarried and had a second child without the virus. "Rimuru" lives with his mother, stepfather, and younger sister today. He finds in his stepfather the father figure that his biological father didn't offer him.

Since childhood, "Rimuru" has been an eloquent boy, revealing a profusion of ideas during the appointments, a whirlwind of thoughts that often left everyone involved with a sense of chaos. His ideas seemed to spring from a rich and complex inner world, some edging near reality, others emerging from a universe of their own, the world of "Rimuru".

His diagnosis was revealed at the age of 10, when "Rimuru" spotted the box of medication. However, an open discussion about the subject with his family didn't take place until he was 12. Now, at the age of 16, he shows great interest in HIV, is an expert on the subject, and can explain how it works in the human body; *"Knowing there's something in my body that isn't mine, and that part of these beings don't let you protect yourself from the beings that want to try to kill you, say, it attacks, but it doesn't attack you to kill you, it attacks you to not let you defend yourself. HIV works more or less like that. It's a virus that directly attacks someone's immune system"*.

Along with the confirmation of his diagnosis, "Rimuru" faced a significant change when he enrolled in a more demanding school. Despite having friendships, he reports facing considerable pressure and academic challenges, struggling to keep up with the pace. *"I've experienced prejudice at school, but it's been random situations. Prejudice is not liking and mistreating what is different. This activity made me think everyone is different"*. At the same time, he receives mental health counseling. On his path of self-discovery, he explores his multiple facets in a journey to find a way to deal with his concerns. *"My sanity is intact, but my emotional and psychological state is a little broken."*

Showing creativity and intelligence, he shares his internal battles, sometimes illustrated with a smile. "Rimuru" shows satisfactory adherence to treatment, attending appointments, and undergoing tests.

The opportunity to participate in the research was received enthusiastically by "Rimuru". He self-declared brown. He was involved at every stage, interacting with the group, listening, and sharing his stories. He participated in the conversation circles, providing a unique insight into the bodily sensations he experienced after this experience: *"Dancing in the hospital is therapy. It's another therapy. We come here to look after our health, and I'm looking after myself"*.

5 - Adopted at the age of six by a couple, "Radock" (that's what he called himself) is a 12-year-old Black boy who started taking HIV treatment at the clinic in 2016. "Radock" is an active and intelligent boy who interacts during appointments. He likes to talk about his interests and defends his opinions. He does well at school, nurtures friendships, and has a passion for soccer. *"I look after myself by making friends"*.

He adheres well to his treatment, attending appointments regularly and taking the necessary

tests. He has no difficulty taking his medication, although he reports that the routine is boring and imposes limits, such as the difficulty of sleeping at his colleagues' houses.

Family is a constant source of love and support in Radock's life. He speaks fondly of his parents' care, especially regarding his health and diet. Visits to his grandmother's house are special moments where he feels free to enjoy treats.

Awareness of his condition, acquired at the age of six when he was adopted, is intertwined with his identity and origin, a theme that permeates conversations about HIV. Although he does not ask many questions and does not express doubts or curiosities about the virus during appointments, "Radock" clearly understands the importance of medication for preserving his life. *"I know how serious it is, and when I came here, I already knew"*.

He was not interested when he was invited to participate in the research. His father stressed that it could be fun, and "Radock" accepted without much enthusiasm. The activity did not seem like a challenge, which bored him. However, his body found a way of expressing itself through dance. *"Some people have trouble dancing, but for me, it was nice and helps relieve stress."*

6 - "Msth" is what this brown 13-year-old called himself. He was adopted at six months old by a couple who had been waiting for this moment for several years. They share a spacious home, a farm in "Msth's" words, together with his younger biological brother, who is not living with HIV and was later adopted by the couple. "Msth" does not remember when he first found out he was adopted. This story has always come naturally to him, but he says his understanding of this reality has gradually been built over time.

A young man of few words during appointments, "Msth" limits himself to answering only what he is asked. According to his family, he does well at school, has friends, is responsible, and contributes to the household chores.

"Msth" discovered his diagnosis at the age of 12 during a conversation at the clinic, in the presence of his parents and the multidisciplinary team. Initially, he showed no curiosity about the virus. *"I thought I had asthma"*. His treatment adherence is good, and he does not express any difficulties in taking his medication. *"It's normal for me to take my medication"*. He attends his appointments and undergoes the necessary tests.

Although he agreed to participate in the research with some trepidation, "Msth" got involved at every stage. Monitored at the outpatient

clinic since birth, "Msth" showed a surprising side during the workshops: outgoing, cheerful, and participative. In this space, he engagingly expressed himself, sharing opinions, mediating relationships in the group, and interacting with everyone, revealing how much he enjoyed the experience. *"I'm not like that. I don't think it's cool, but I liked it. I arrived here tired and slow, and I'm doing better"*.

7 - "Nillu" started being monitored at the outpatient clinic at the age of 2 years and 7 months, shortly after the family learned of the diagnosis, which not only covered her condition but also that of her mother and father. The first steps were challenging, involving a series of adaptations and the absorption of complex information. Initially, "Nillu" was resistant to medication, but acceptance of her health condition stabilized gradually as the family came to understand the situation better.

Currently 13, "Nillu", as this boy chooses to be called, is consistently adherent to treatment, regularly attending appointments and taking the necessary tests and medication. He lives only with his mother, who is separated from his father. He is an only child on his mother's side and the youngest on his father's side. Even with the separation, "Nillu" lives with his father whenever possible.

"Nillu" self-identifies as brown, a shy young man of remarkable stature, which often makes him visible, although he seems to try to hide in shame. During appointments, he answers questions at his own pace, sometimes seeming not to fully understand what has been asked, resulting in silent pauses. However, when the subject enters his world of drawings, games, and music, he frees himself and expresses himself eloquently, sharing his passions. Showing a remarkable talent, "Nillu" has an exceptional ability for drawing and shows off his productions enthusiastically. He struggles to keep up with some subjects at school but is advancing. He also enjoys friendships and the school environment.

He learned of his diagnosis at home during a conversation with his mother. He does not remember the exact age at which it happened, and the record in his medical records indicates that the conversation occurred in early 2022. Curiously, although it was less than a year ago, during the research, "Nillu" spoke about this revelation as if it had happened a long time ago, to the point where he no longer remembered the moment. In other words, he wanted to forget. *"I'm scared of having this HIV"*. It is remarkable that he did not

ask questions or was curious about the virus. “*I didn’t ask anything because I didn’t have the courage*”. He often claims not to remember the name of his condition, leading his life as if living with the virus had not interfered in his trajectory. “*It hasn’t changed anything, but now that I know, I’m more focused on the medicine, and that’s good*”.

“Nillu” readily accepted the invitation to participate in the research, committing himself and attending all the proposed stages. He gave himself over to the movements and let himself be carried away by the rhythms, sharing with the group his positive feeling of fun at participating in the experience. “*It was a cool game*”.

8 - “Barbie” is how this 16-year-old brown girl named herself. She started attending the clinic at the age of 7 when her mother’s HIV diagnosis was discovered. Separated from her biological father since “Barbie” was a year old, her mother remarried and had a son who does not carry the virus, thus forming Barbie’s family with her stepfather and younger brother.

Although she has to deal with a complex health condition, having HIV and a chronic condition that requires intensive care, “Barbie” faces her reality with resilience. Besides HIV treatment, another specialized hospital follows up on her other condition. Her life is permeated by doctor’s appointments, tests, and countless hospitalizations, some brief and others longer. “Barbie” carries a backpack containing her several medications, which she describes with natural ease. “*It’s normal for me. I’m used to it*”.

Despite the adversities and routine altered by her health condition, “Barbie” is a cheerful, fun-loving, humorous, and laughing young woman. She shares aspects of her life, friendships, and love experiences during her appointments. She can keep up with her studies at school, even in the face of frequent absences due to hospitalizations. Adherence to treatment remains optimistic despite the occasional need to reschedule appointments and delay tests, ensuring that HIV is under control.

She has a crucial support network, made up of a mother and grandmother who are dedicated to her care. Revealing the diagnosis was a challenge. It was permeated by the guilt of her mother, who experienced a painful dilemma when she unknowingly transmitted the virus. The frank conversation about the diagnosis occurred when “Barbie” was 14, and her reaction was surprisingly accepting. “*I felt good when she [her mother] told me. I felt calm*”. During appointments, she asks questions and clarifies doubts about the vi-

rus, reporting that the revelation strengthened her bond with her mother.

“Barbie” actively participated in the research, involved in all the proposed stages. She showed dance skills, flowing in tune with the rhythms presented. During the workshops, she shared her story, met other patients, and interacted intensely with them. “*I liked it. It was different and cool. I came here a mess, and I’m leaving much better*”.

Reflections on Life Stories

Analyzing the accounts of these young people who share the same social context, face the situation of living with HIV, and share an infection through vertical transmission (mother-to-child) revealed aspects of this event by identifying the similarities and differences in their stories, which allowed us to explore the experience’s individual and social aspects.

The life stories of these young people begin to unfold from their family contexts, where the individually distinct dynamics have some notable similarities. One prominent feature is the predominance of maternal care, often exclusive, resulting in an overload for mothers. Society makes this care invisible and reflects the cultural representation of the responsibility attributed to women, especially mothers and grandmothers. The most frequent feature is the absence of a father figure. This event is reported in the works by Kaunda-Khangamwa *et al.*⁴ and Ramos *et al.*⁵. The authors point out that, in sub-Saharan African countries, young people with HIV often live in families where most care responsibilities lie with women.

Besides, women living with HIV who transmit the virus to their children often experience a deep sense of guilt. They are often stigmatized for alleged morally deviant behavior. A study conducted in Uruguay⁸ notes that HIV-positive pregnant women face increased stigma, where the disease is assessed in terms of a hierarchy of categories ranging from purity, symbolized by children infected by the virus through the mother, to the supposed guilt of those mothers who contracted the virus through sexual means⁸. As Parkson and Aggleton²² point out, we should emphasize that stigma is not merely an attribute imposed by one individual on another, but a social process intrinsically linked to perpetuated power and control relationships.

Another relevant aspect that emerges from the stories shared is the persistent orphanhood resulting from HIV. Despite the reduced mortality

ty caused by the virus in recent decades, orphanhood is still a reality among young people affected by the epidemic. Four of the eight participants in the study have lost their biological parents and live with adoptive families.

The issue of orphanhood among young people affected by HIV was also observed in studies in Tanzania⁵ and Uganda²³, where most young people interviewed reported having lost one or both parents. The need to adapt to different family contexts, including living with adoptive parents, stepfathers, or stepmothers, was not perceived as something that hindered acceptance of the disease, nor was it an impediment to adherence to treatment. On the contrary, research shows that adoptive families are an essential and effective support for the interviewed young people.

Another piece of information worth highlighting concerns the epidemic's demographics. Seven of the eight participants said they were Black or brown. This trend is also corroborated by a study conducted in France²⁴, where most HIV cases involved young Black people of African origin. Furthermore, all these young people belong to economically disadvantaged social strata, which aligns with the study in France²⁴, signaling a trend towards impoverishment of the HIV-affected population, which makes young people more vulnerable due to their low socioeconomic status and limited access to quality education. People living with HIV often blame themselves for a disease that is often related to poverty, as observed in the research conducted in Uruguay⁸.

In contrast to studies from sub-Saharan Africa^{4,5,23}, where extreme poverty is a predominant reality, although young people in this study live in a low-income situation, they do not report severe issues such as hunger or poverty. Their financial concerns were related to the desire to improve their quality of life, acquire material goods, and enjoy more leisure time.

Regarding sexuality, studies conducted in Brazil²⁴ and Uruguay⁸ point out that the discussion of this topic lacks an adequate approach in schools, is often repressed, and neglects the adolescents' experiences and anxieties. The discourse that imposes behavioral rules prevails, and the transition from childhood to adolescence is viewed with concern, especially concerning young people living with HIV, who are considered a "danger"⁸. In Brazil, adolescents are immersed in intense eroticization promoted by the media, creating a paradox in which they are encouraged to explore their desires early while

being confronted with messages that disapprove of sexual activity in adolescence²⁴.

According to Taquette²⁴, this situation differs from the French reality, where sex education is discussed more openly in schools. The author considered this factor as a favorable element in reducing the risk of vulnerability of adolescents with HIV.

Despite the sex education-related issues, school is described by all the participants in the study as a place for socialization, interaction, and establishing meaningful bonds. Although young people face hardships and conflicts, school should be considered a safe, receptive, and inclusive place for everyone, regardless of their health condition.

The narratives shared by young people reflect the constant search for normality in their lives, wanting to establish routines similar to those of their peers. However, the daily need to take antiretroviral drugs disrupts this search. All the participants in the study mentioned that these drugs interfere with their daily routines. They also serve to remind them of the constant presence of the virus in their lives.

The complexity of these young people's needs leads us to reflect on the clinical environments in health services. The study carried out in Malawi⁴ shows that services adapted to the needs of adolescents contribute to adherence to antiretroviral therapy and result in undetectable viral loads, consequently improving their quality of life.

When provided with a friendly space, adolescents can talk about their lives and interests, which also contributes to their resilience in coping with HIV. While not the focus of the study, mediation through circle dance offered a safe and playful space to express feelings and emotions through body movements, promoting belonging and connection with the group, which was recognized by all.

A notable characteristic of the group studied is their willingness to recognize their challenges, motivation to overcome them, and ability to make decisions.

We, therefore, conclude that the results of this study challenge the common narratives associated with adolescents living with HIV. They emphasize their positive choices, the creation of meaning in their lives, and their ability to ask for help in the face of difficulties. The research's limitations were addressing a small group. However, as Adorno and Horkheimer²⁵ point out, the researcher must find all humanity in individuals and any group.

Collaborations

The authors participated in the conception, analysis and interpretation of data, writing of the article and approval of the version to be published.

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Article submitted 29/11/2023

Approved 27/03/2024

Final version submitted 29/03/2024

Chief editors: Maria Cecília de Souza Minayo, Romeu Gomes, Antônio Augusto Moura da Silva