

## HIV-related stigma among young people living with HIV transitioning to an adult clinic in a public hospital in Rio de Janeiro, Brazil

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**Abstract** *This study analyzes how experiences of HIV-related stigma are expressed among HIV-positive young people transitioning to an adult clinic, the health service, the family, the affective-sexual interactions, and their relationship with inequalities and social hierarchies. This research included 31 young people (median age 21) transitioning to an adult clinic (G1) and 12 young people (median age 30) who had already made this transition (G2), both monitored at a health service in Rio de Janeiro. Seventy percent of the 43 young people were women and 65% were infected by mother-to-child transmission. Young people answered questionnaires and participated in focus groups on AIDS stigma and transition to adulthood. Most reported discrimination associated with HIV stigma in daily life and health care. G1 young people showed more significant concern about the consequences of HIV disclosure and difficulties with treatment. The G2 accounts suggest that establishing marital relationships, including HIV-negative partners and children, linked to treatment access allowed resignifying the fear of stigmatization. The findings aim to guide the training and action of professionals involved in the prevention and care of young people living with HIV.*

**Key words** *Stigma, AIDS, Young People Living with HIV, Transition to Adult Care*

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## Introduction

One of the crucial achievements in facing the AIDS epidemic is advancing antiretroviral therapy (ART) and its impact on increasing survival and improving the quality of life of people living with HIV/AIDS (PLWHA), including children and young people. Thus, the teams involved in the care of children living with HIV saw the emergence of a population of young people requiring continuous pediatric care. Health professionals, managers, and researchers have developed discussions about the specific needs of this emerging population<sup>1-3</sup> globally. As a result, health services have been adapted to address aspects such as disclosure of the diagnosis since childhood; opening and flexible schedules to facilitate appointments; multidisciplinary work to respond to different demands; counseling on adherence, and group activities to create a supportive environment where young people can develop their skills to address the difficulties of living with HIV and other adolescence-related issues.

The implementation of policies and guidelines for the prevention and care of young people living with HIV/AIDS (YPLWHA) varies globally, depending on the specificities of local contexts. Despite this, many of these young people reach adulthood with advanced disease and extensive ARV resistance, with a significant portion abandoning treatment<sup>4-6</sup>. These aspects must be considered when planning the transition of YPLWHA to the adult clinic to pursue their treatment.

Regarding chronological age, Brazil has no strict rule for the effective transition to the adult clinic. In general, the team evaluates each young person considering aspects related to understanding the diagnosis, the ability to discuss health issues, autonomy, and organization in the face of the demands of their treatment and adult life<sup>7</sup>. The perspective that the transition to the adult clinic is a process that should consider subjective, social and life stories, prevails.

In this sense, it is troubling to note that, not infrequently, young people resist when informed about the need to be followed up in another clinic. Adverse reactions to the transition process are expressed by the threat of abandoning treatment and refusing to attend visits at the adult clinic. Such situations have been observed during care practice in an infectious disease service in a public hospital in Rio de Janeiro, where two authors (MLSC and MD) work as professionals in the medical and psychology fields. It should be noted that, in general, transitioning to an adult clinic in

several reference centers, inside and outside Brazil, occurs over six to twelve months, with outpatient appointments interspersed in the youth and adult sectors. The teams responsible for the two sectors usually interact throughout the transition to facilitate the process. However, studies have pointed out that some factors are unfavorable to the transition, such as difficulty in adhering to treatment, HIV stigma, low self-esteem, lack of autonomy, substance abuse, and mental health problems<sup>7-11</sup>.

Faced with the implications of AIDS stigma for the quality of life of people with HIV, this study aims to investigate how HIV stigma experiences are expressed among HIV-positive young people transitioning to an adult clinic within health services, family relationships, and affective-sexual interactions, and their relationship with inequalities and social hierarchies. The study involved YPLWHA in transition to an adult clinic and young people who had already made this transition, both seen at a public hospital in Rio de Janeiro. The study results aim to obtain supporting elements for the professionals involved in the prevention and care actions of this population. Such a selection is justified given that HIV-related stigma is an essential obstacle to developing adaptive coping and social support, including the transition to an adult clinic, as it enhances the risk of mental health problems, reduces self-efficacy, and increases concerns about disclosing HIV status<sup>12,13</sup>.

Reflection on the implications of HIV-related stigma, part of Goffman's pioneering study<sup>14</sup>, which defines stigma as a disqualifying attribute. According to the author, in social interactions, the stigmatized individual tends to be segregated from the so-called "normal" people, hindering the valorization of their other characteristics<sup>14</sup>. Stigmatized people may develop inhibitory behaviors or incorporate a negative self-image, contributing to their isolation and reinforcing stigma.

Other authors recognize the relevance of the concept of stigma but try to highlight its social function, arguing that stigma plays a fundamental role in the production of power and control relationships. In other words, although apparently arbitrary, in general, defining an attribute as negative is related to hegemonic aesthetic, social, and cultural patterns<sup>15,16</sup>. According to this perspective, stigmatization processes create barriers that compromise the access of stigmatized individuals or social groups to material and symbolic goods and sustain social hierarchies and inequalities. Thus, understanding the stigma linked to a health

problem should consider how the particularities of this condition are linked to social markers of difference such as social class, gender, skin color/race/ethnicity, and sexual diversity.

The case of AIDS-related stigma is exemplary. Its origin is linked to the association between HIV infection and morally deviant sexual practices, the lack of knowledge of the scientific community in the face of the new problem, and the infection's fatality at the onset of the epidemic. These factors triggered moral panic and fueled the discrimination and social exclusion of PLWHA, hampering their continued care access. Marked by biomedical, political, and PLWHA rights advances, the AIDS stigma persists after 40 years and compromises prevention and care achievements, which leads us to the complex event and its association with other discriminatory processes such as homophobia, sexism, social inequalities, and structural violence<sup>17</sup>.

Bearing in mind that addressing the stigma associated with AIDS must include actions at the micro and macro-structural level, it is essential to highlight how it impacts the lives of PLWHA. The statements of YPLWHA in transition or already transferred to an adult clinic will make us understand how HIV-related stigma is expressed in the daily life and health care of this group. The findings aim to guide the performance of professionals involved in the transition of YPLWHA to the adult clinic.

## Methods

This is a cross-sectional study with quantitative and qualitative data on young people living with HIV, monitored at an outpatient clinic of a federal hospital, transitioning to an adult clinic or who have made this transition in recent years. The hospital is located in Rio de Janeiro and has hosted a clinic for YPLWHA since 2000, where patients receive interdisciplinary care and participate in group therapeutic activities. Since 2005, the service has also monitored children living with HIV.

The infectious disease outpatient clinic service (DIP) at the hospital receives patients aged at least 11 years old, referred from pediatric follow-up, where the vast majority had HIV transmission in the perinatal period (mother-to-child transmission or MTCT). The outpatient clinic also receives YPLWHA referred from clinics of sexually transmitted and prenatal care infections who have acquired HIV through sex (ST). It is

impossible to clearly identify the HIV acquisition route in some cases, and young people are classified as with an undetermined transmission route (UT).

The participants in this study are YPLWHA monitored at the Hospital's DIP aged at least 18. The study involved two groups of YPLWHA to understand the discrimination experiences associated with HIV stigma before and after transitioning to an adult clinic. The first consisted of 31 young people in transition to the adult clinic, hereinafter referred to as G1, with a median age of 21 years. The second group consisted of 12 young people followed up at the outpatient clinic transferred to the adult clinic in recent years, hereinafter referred to as G2, with a median age of 30. The invitation to participate in the research occurred in both groups as young people came to the service for their regular appointments.

The study was approved by the institution's Human Research Ethics Committee and followed the guidelines of Resolution 196/1996 of the National Health Council, such as the application of the Informed Consent Term among the participants.

The young people recruited were invited to participate in the study's qualitative component, consisting of two focus groups (FG)<sup>18,19</sup>, one with G1 and the other with G2. The FGs' roadmap stirred discussions about how they address changes related to adulthood, how they express what they identify as gains and losses in this emerging phase, and whether they feel or perceive any difference from other people because they were living with HIV. Each focus group was led by researchers (psychologist and doctor) and was held at the service in a space for group activities. The thematic analysis of the content of FGs was conducted and targeted the core meanings of the topics covered, such as the changes resulting from entering adult life and the experiences of discrimination associated with the HIV stigma in the context of care, social, and family relationships, and affective-sexual interactions<sup>19</sup>.

Besides the focus groups, the 46 young people in the study answered the following validated instruments: sociodemographic questionnaire, HIV stigma scale<sup>20</sup>, and the Hospital Anxiety and Depression Scale<sup>21</sup>. These instruments were applied by two members of the multidisciplinary team (nurse and psychologist). An index was calculated for each subscale of the Berger HIV stigma scale, dividing the actual score by the total possible score for the respective subscale, as published by other authors<sup>22</sup>. The data were

stored and analyzed using SPSS version 18.0, and frequencies, means, and median values were calculated for descriptive purposes. The medical records of these young people were also consulted to obtain the viral load and CD4 results. The data from the quantitative instruments and the medical record aimed to complement the information collected during the focus groups timely.

## Results and discussion

The study was conducted from April 2017 to February 2019. During this period, 90 young people aged 11-26 years were receiving care at the outpatient clinic for YPLWHA at the hospital referred to in the methodology. All of the 43 young participants (31 from G1 and 12 from G2) belonged to low socioeconomic strata, with an average household income of about 1.7 Brazilian minimum wages and, despite having studied on average for 14 years, none had higher education.

The small sample size does not allow statistical comparisons. The difference in median age between G1 and G2, 21 and 30 years, respectively, in turn, introduces variations associated with the moment of life's trajectory. In any case, based on the results of the quantitative instruments and focus groups, we could identify aspects related to living with HIV and the treatment of young people belonging to G1 and G2 and about their experiences associated with AIDS stigma.

### Living with HIV

Medical records revealed that the discovery of HIV infection among the G1 and G2 YPLWHA varied, as some occurred in childhood and others in adolescence. As Cruz et al.<sup>11</sup> argue, the disclosure of the HIV diagnosis and social and family context influence the primary socialization of infected children and adolescents and, consequently, their experiences on the condition of being an HIV carrier. According to the authors, asymptomatic adolescents subjected to HIV testing due to their mother or father's diagnosis of seropositivity react differently. Some adhere to the treatment, while others struggle to accept this new condition.

The data collected in this study do not consider further details on the life trajectory of the 46 YPLWHA that are part of the study but allow identifying experiences related to the stigma of HIV throughout life. As the percentage data in Table 1 indicate, young people in G1 and G2 have

similarities regarding the anxiety and depression levels and the Berger scale scores for HIV-related stigma. This scale consists of 40 questions related to rejection experiences, concern with disclosure, negative self-image, and the perceived social rejection associated with HIV, which has four response options: totally disagree, disagree, agree, and totally agree.

The analysis of the statements during the two focus groups with young people from G1 and G2 also indicated situations of discrimination within health care in recent years. Participants in both groups reported hostile attitudes by health professionals either during hospitalization or in the medical care experience. The following accounts are illustrative:

*... I went through much prejudice in the maternity hospital where my son was born. It was much prejudice. I had a nurse coming to me and say: "How old are you?" So, I said, "sixteen". To which she replied, "You ruined your life. Don't you ever do anything without a condom again". That is how it was. Every time she came in and hit me with a "cold shower". I was in a room where I was the only one with HIV. Everyone else was breast-feeding, which was something that still affects me because I wanted to breastfeed ... Because a pregnant woman with HIV is a little different from the normal one. (M. 21 years old, fem, ST, G1).*

*Well, they put me in a separate room because I have this thing [HIV]. They said that some people have this disease and have to stay in a separate room. Also, that woman didn't want to make the dressing. (A. 22 years, MTCT, fem, G1).*

*[...] then the doctor said "because she is seropositive; these people had to die and stuff like that. (S. 30 years old, fem, MTCT, G2).*

Although such situations cannot be generalized, noteworthy is the recurrence of these statements among the G1 and G2 YPLWHA and their effects in updating the experiences of discrimination of PLWHA. The two authors of this study (MLSC and MD), who work in the care of YPLWHA, as already mentioned, argue that it is common for young people with a recent diagnosis or who do not have good adherence to treatment to miss appointments. Authors believe that the non-attendance to the service may be related to the fear of being judged by health professionals.

Other studies have registered discriminatory practices of health professionals with PLWHA<sup>23-26</sup>. One U.S. study<sup>23</sup> highlights that the professionals' stigmatizing practices can be triggered by fear, lack of training and specific education about HIV, and limited contact with

**Table 1.** Description of the characteristics of the young people included in the study: G1 (in transition to the adult clinic) and G2 (had made the transition in recent years).

Characteristic	G1	G2
Median age	21 [IQR=19-22]	30 [IQR=25-31]
Female	68%	83%
Non-white	77%	100%
MTCT-acquired HIV*	71%	50%
Unemployed	74%	59%
Undetectable viral load in the last exam	48%	50%
Anxiety	57%	54%
Depression	13%	15%
Berger's scale for HIV-related stigma		
Rejection experiences**	0.56	0.6
Concerned with revelation**	0.66	0.7
Negative self-image**	0.7	0.67
Perceived social rejection**	0.67	0.65

\*MTCT: Mother-to-child transmission. \*\* Scores were calculated by dividing the actual score by the total possible score for the respective subscale.

Source: Elaborated by the authors.

PLWHA. The studies and findings described point to the need and importance of investing in professional training, coupled with cultural interventions to give AIDS stigma visibility, which have been scarce in recent years.

Regarding the impact of stigmatization on people with undesirable marks, studies indicate that such situations encourage negative self-assessments and self-rejection and threaten the stigmatized subject or social group's social identity<sup>27,28</sup>. In the case of HIV stigma, research attests to reactions of guilt, shame, fear, anger, and refusal to accept the diagnosis, which causes depression, social exclusion<sup>29</sup>, and compromise treatment adherence.

In this sense, it is worth mentioning that G1 participants indicated more significant concern regarding the consequences of disclosing their HIV status when compared to the G2 members.

The following statements exemplify experiences and views about the fear of disclosure of the diagnosis:

*For example, I had a best friend. I thought she was. In the end, she screwed me up, right? She kind of told all people on the street what I have. I'd rather have an enemy than such a friend. (A. 22 years old, fem, MTCT, G1).*

*I don't say anything. Today, I am ready to open my mouth and speak out if anyone asks or finds out. Sometimes I even feel like posting it on Facebook [...] Actually, if I say it, it will be a shock, right? People will enquire "how so?" [...] It makes me want to talk more when I'm drunk. To pick up the microphone and say "hello, hello ..." [...] It almost comes out, but he never does, really. However, everyone will think that I'm drunk and talking nonsense the day I tell everyone because I do talk nonsense... (T. 25 years old, fem, MTCT, G1).*

A previous study with children and adolescents living with HIV in different Brazilian regions<sup>30</sup> confirms other literature indicating that the difficulty of disclosure tends to compromise treatment adherence. Thus, it is essential to consider that young people in G1 reported more significant discomfort with the continued use of the medication. A G1 participant, aged 20, had a late diagnosis of mother-to-child transmission at age 12, discovered on the occasion of the mother's new pregnancy, which resulted in the testing of other family members. She reports that using the medication makes her look like an anemic person for making her eyes yellow. As a reaction, she hides the HIV infection, preferring to say that she goes through economic hardships: "there is no food at home. It is hard, and unemployment is out there, right?"

Another 25-year-old G1 participant had her diagnosis and adoption revealed in her teens at 15. Since then, she claims that she is different from other people in attending medical appointments and taking medication to ensure her survival. In her statement, "I have to go to the doctor. I take medicines, and if I don't take them, I die. I depend on two drugs", it appears that the continued use of medicine throughout life, in general, can promote discomfort due to side effects and frequent medical follow-up.

However, due to the AIDS stigma, people with HIV undergoing treatment live with the fear of being discriminated against if they reveal their infection. This means that even with the recognized benefits of the continued use of medication to stay alive, such a process can be interrupted by the fear of discovering seropositivity.

As already described by Goffman<sup>14</sup>, the reactions to the stigmatization process can be social isolation, self-depreciation, and management of the undesirable mark, through its concealment or correction, seeking social acceptance and reducing tensions in interactions with the so-called “normal” people. Failure to disclose the HIV diagnosis illustrates this attempt to erase the stigmatizing mark. However, the stigmatized have other ways to react, such as establishing help and mutual support networks and political action through the fight for the rights of people with stigma. The history of the responses of the PLWHA social movement illustrates these phenomena<sup>31</sup>. The current weakening of AIDS social movement in the national context, in part because of the reduced resources, has compromised social control and the formulation of prevention and care discourses and practice, including the confrontation of the AIDS stigma.

#### **Resignifying the AIDS stigma after the transition to the adult clinic**

Differences were identified despite similarities noted between G1 and G2 members. One of them refers to the item ‘unemployed’ in Table 1, where the percentage of G1 (74%) is higher than G2 (59%). The median age of young people in G2 being higher than G1 (30 against 21 years) suggests that G2 members are more likely to be engaged in work activities.

Another difference between the two groups is related to the fact that the statements of young people in G2 do not refer to problems associated with the continued use of treatment, as reported by G1 in the item above. Moreover, the reports of YPLWHA of G2 suggest that establishing marital relationships, including a partner and seronegative children, linked to access to treatment, allows resignifying the fear of HIV stigmatization and, somehow, overcoming the history of illness resulting from infection and fear of transmission. The accounts below are illustrative:

*However, I cannot complain. I didn't have a father and a mother since I was a child. I was raised in the shelter. Then, the Juvenile Court ordered me to move in with my aunt when I was practically an adolescent. I stayed there a long time too. I felt down to the bone what it is like to... get sick all of a sudden because you look out for the medicine because there was no medicine for you, being thrown from one hospital to the next, submitted to endless tests, and feeling bad. My adult life after my daughter was born for me is better when it comes to med-*

*ication. I don't have the disease out of the blue, so for me, it is ... the husband who is not seropositive also has nothing. He helps a lot. We have our own house now, and everything is fine. Our daughter is already reading: she has grown. It is the value we have to give to those who helped us when we were adolescents... (S. 30 years old, fem, MTCT, G2).*

*Not at first: let us say in the first five [...] sometimes I thought, I went dating. Then I looked to myself and said: My God, so and so, it will be different. I have to use a condom because if I don't, then I transmit it to the guy, and the guy will find out he's going to want to kill me, so and so [...] Thank God, today I have my family. I have my husband. My husband is not seropositive, you know. He does the test every year properly. One thing that also encourages me to take medicine is taking care of myself to not transmit it to him; it is also an incentive. Today, I don't feel any different from anyone else. I arrive at a place where I'm at. Those who know, know. If they don't and also don't want to, I say it. It doesn't make a difference to me if they know that I have it and if they don't; it makes no difference. (P. 30 years old, women, ST, G2).*

*... when I met my wife, I felt so confident in her that I think after two days of dating I got to the room and said to her, “we have to talk”. I explained to her, with fear of her leaving me and so on. Then she simply hugged me. We got up and went out. She always supported me, “hey, we're together!” Today I try to take care of myself. I take care of myself but sometimes it is about not transmitting to her, you know. (M. 25 years old, masc, UT, G2).*

These statements converge with the results of a study that explored the intimate relationship experiences of 1,334 women living with HIV in Canada, where women with HIV-negative partners had greater feelings of normalcy and those in happy long-term relationships were less likely to experience stigma<sup>32</sup>. While the causality of these observations cannot be determined, the authors believe that the effects of the love relationship and intimacy on psychological well-being may, in part, explain these findings. On the other hand, the association between the difficulty of establishing affective-sexual relationships and the fear of HIV-related stigmatization was evidenced in studies with young MSM in Chicago<sup>22</sup> and South Africa<sup>33</sup>. The findings revealed that young people who fear rejection because of their HIV status are more likely to be socially isolated and not get involved in romantic relationships.

In this sense, it is interesting to highlight that part of the young people who made the transition was involved in affective relationships with

seronegative partners. They experienced motherhood/paternity with the prospect of not transmitting HIV to their children to access medications preventing mother-to-child transmission, meaning that they had an opportunity for HIV prevention in reproduction that their mothers did not.

It can be assumed that establishing marital relationships, generating seronegative children (due to the prevention of mother-to-child transmission), and the lack of signs of HIV infection (resulting from treatment) bring PLWHA closer to a “normal” standard. These situations contribute to erasing the stigmatizing AIDS “mark” that generated situations of discrimination throughout life. Considering that several studies attest that the experiences of stigmatization associated with HIV are common and generate suffering, it is understandable that the erasure of stigmatizing marks reduces discrimination and is desired by PLWHA.

However, as Monteiro et al.<sup>34</sup> argue, it is necessary to stress that the lack of visibility of factors that gave rise to and promote the AIDS stigma, as highlighted in the introduction, contributes to its persistence. In other words, coping with stigmatization by hiding or erasing the mark can reduce the suffering of stigmatized people. Nonetheless, it does not favor questioning what makes this mark something exceptional to be hidden. Thus, it is essential to recognize that the deconstruction of the AIDS stigma will not result from individual actions isolated from PLWHA, but from a group effort, through cultural and structural policies and interventions<sup>17</sup>. In this sense, the lack of continuous investments to address the stigma and conditions of vulnerability to HIV in the current national and international guidelines for responding to the AIDS epidemic is of concern. Such recognition has ensued proposals for actions to this end<sup>35</sup>.

### Final considerations

The study results with HIV-positive young people, either in transition or already transferred to an adult clinic, enable a better understanding of the challenges of living with HIV among young

people and their effects at different stages of progression to adulthood. Thus, it can guide the training and action of professionals involved in the prevention and care of YPLWHA.

The fact that YPLWHA in transition to the adult clinic indicates more significant concern about disclosing the diagnosis, which could affect adherence to treatment and the transition to an adult clinic, suggests the importance of health services addressing this issue. From this perspective, we propose that professionals promote a continuous dialogue with YPLWHA about the factors involved in the emergence of the AIDS stigma, the reasons for its persistence, and the possibilities of coping at the micro and macro levels. It may be relevant to involve in this dynamic young people who have already completed the transition to share their trajectories of living with HIV, including the current situation regarding the prospects of conjugality, motherhood/paternity, labor integration, and adult life challenges. It is worth mentioning that resignifying AIDS fatality and expanding PLWHA's life expectancy was one of the factors associated with greater adherence to treatment, according to research with children and adolescents with HIV, from pediatric AIDS treatment units in five Brazilian macro-regions<sup>30</sup>.

As argued, AIDS stigma is a complex phenomenon whose persistence has compromised the achievement of relevant goals in prevention and care. Its coping involves structural, cultural, and psychosocial interventions. Health professionals involved in the prevention and care of PLWHA could collaborate in denaturalizing this phenomenon. Thus, it is necessary to recognize the origin and social function of the AIDS stigma and invest in continuing education to address the historical, cultural, socioeconomic, and political dimensions of the epidemic, besides biomedical intervention.

Indeed, this is a great challenge, given that such aspects, in general, are not considered in the graduations and specializations of health professionals. However, the four decades of the epidemic provided lessons and learnings to approach these themes in the formation of teams and, consequently, in the performance of health services working with PLWHA.

## Collaborations

MLS Cruz proposed the work, presented the initial version of the project, coordinated the FGs, worked on analyzing the contents of the FGs, and presented the preliminary version of the final manuscript. MQR Darmont contributed to the writing and development of the project, coordinated data collection, observed the FGs, worked on the analysis of the contents of the FGs and contributed to the writing of the final version of the manuscript. SS Monteiro contributed to the writing and development of the project, worked on analyzing the contents of the FGs, and contributed to the writing of the final version of the manuscript.

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