

# Reports on a book with situations of stigma/discrimination of People Living With HIV/AIDS in Brazil

*Relatos sobre um livro com experiências de estigma/discriminação de Pessoas Vivendo com HIV/AIDS no Brasil*

Daniele Souza<sup>1</sup>, Carla Pereira<sup>1</sup>, Juan Raxach<sup>1</sup>

DOI: 10.1590/0103-11042022E7191

**ABSTRACT** Related to the activities of the Brazilian Interdisciplinary AIDS Association in 2021, the project ‘What if it was with you? Lived Stories of Stigma and Discrimination in 40 Years of HIV/AIDS’ was developed. The project aimed gathering real stories of stigma and discrimination, but also presenting the traumatic experiences lived by people with HIV/AIDS, and stimulating empathy and solidarity around the group. This article is a report on the experience of the project, carried out by calling volunteers on the social networks of the Association. Among the volunteers, ten individuals were selected, considering types of situations experienced, age groups, genders, races, sexual orientations, and origin, trying to show different aspects of living with HIV/AIDS in Brazil. To guide the interviews, a semi-structured script was prepared, with dozens of questions adapted to the individualities of each participant, to address different life stories. From the interviews, ten different stories were written, punctuating situations of stigma and discrimination, in different moments of life, as well as frames of confrontation and resistance. On the occasion of World AIDS Day in 2021, the book was launched at the same Association’s seminar ‘Refazendo a Prevenção’, and it is available for free download.

**KEYWORDS** HIV. Social stigma. Social discrimination. Life history traits. Brazil.

**RESUMO** Ao longo de 2021, no âmbito de atividades da Associação Brasileira Interdisciplinar de AIDS, foi desenvolvido o projeto ‘E se fosse com você? Histórias vividas de estigma e discriminação em 40 anos de HIV/AIDS’. O projeto buscou reunir histórias reais de estigma e discriminação, bem como mostrar traumáticas experiências vividas pelas pessoas com HIV/AIDS, para estimular a empatia e a solidariedade em torno do grupo. Este texto é um relato sobre a experiência do projeto, realizado por chamada de voluntários nas redes sociais da Associação. Entre estes, foram selecionados dez indivíduos, considerando tipos de situações vividas, faixas etárias, gêneros, raças, orientações sexuais e regiões de origem, para tentar mostrar diferentes aspectos de viver com HIV/AIDS no Brasil. No intuito de nortear as entrevistas, foi preparado roteiro semi-estruturado, com dezenas de perguntas adaptadas a individualidades de cada participante, para abordar diferentes histórias. A partir das entrevistas, foram escritas dez histórias diferentes, pontuando situações de estigma e discriminação em distintos momentos da vida, assim como quadros de enfrentamento e resistência. Por ocasião do Dia Mundial de Luta contra a AIDS em 2021, o livro foi lançado no seminário ‘Refazendo a Prevenção’, da mesma Associação, e está disponível para baixar gratuitamente.

**PALAVRAS-CHAVE** HIV. Estigma social. Discriminação social. Traços de história de vida. Brasil.

<sup>1</sup>Associação Brasileira Interdisciplinar de AIDS (ABIA) – Rio de Janeiro (RJ), Brasil.  
danisorris@hotmail.com

## Introduction

In Brazil, epidemiological data<sup>1</sup> indicated that 79,217 new HIV infections were diagnosed in 2019 – 41,909 new cases of HIV and 37,308 cases of AIDS – totaling 1,045,355 cases of AIDS by June 2021. There is, however, an underreporting of new cases in function of COVID-19<sup>1</sup>. AIDS deaths totaled 360,323 deaths by the end of 2020, with a decrease of 29% in the last decade<sup>1</sup>, although at very high levels, with 11 states of the federation having a much higher coefficient than the national one, of 4.1/100 thousand people. Despite biomedical advances in HIV prevention, Antiretroviral Therapy (ART) and this drop in the mortality rate, stigma and discrimination against People Living With HIV/AIDS (PLWHA) remain a reality in the AIDS epidemic.

In addition, the disease itself is still considered an epidemic even today by the Joint United Nations Program on HIV/AIDS, in addition to the new variants emerging in the world<sup>2</sup>. Prejudices and discriminatory actions against people and groups increase vulnerability to HIV and other health problems. International AIDS conferences have identified the persistence of HIV-related stigma as a major obstacle to treatment and prevention. The fear caused by the lack of knowledge about HIV infection, negative attitudes and judgments towards People Living With HIV/AIDS persist, despite decades of information and awareness campaigns about HIV/AIDS<sup>3-5</sup>. Populations most vulnerable to HIV faced stigma due to the association established between the virus, the disease and social markers of difference, such as: gender identity, sexual orientation, race, origin, for example. Added to this were moralized practices related to sex and drug use. Stigma towards People Living With HIV/AIDS, or at risk of contracting the virus, leads to discrimination in all sectors of society, discouraging people from accessing

health services, including methods of prevention and knowledge of serological status for the HIV. Studies on stigma and discrimination show that PLWHA who feel stigmatized are 2.4 times more likely to delay starting medical care until they become very ill<sup>1</sup>. Stigma also influences the decision to seek prevention and testing services early<sup>3</sup>. Therefore, it is urgent to expand actions to respond to stigma, within the framework of human rights.

With regard to the concept of stigma and discrimination, stigma can be considered a condition of the individual who has been excluded from ‘total social acceptance’, acquiring a ‘mark’ that is considered derogatory, such as HIV infection<sup>4</sup>. From the idea that a person should not be in the social environment, discriminatory action occurs, seen as an attempt to exclude certain individuals from society<sup>5</sup>. Stigma and discrimination can lead to a worsening of the quality of life of PLWHA, affecting their relationships with family members, friends, love and work relationships, causing dismissal, worsening of the financial situation and even impairing adherence to ART<sup>6,7</sup>.

With that in mind, the initial idea was to create a book with short, empathetic stories, in accessible language, capable of showing the reality of PLWHA in its nuances, bringing elements of personal life, childhood, work, which make up a human being beyond the marker of a virus and a disease. Stories that could ‘blend’ with the lives of so many other readers, with or without HIV, to encourage identification and solidarity – and because of the fact that the book provides correct information about the infection, the epidemic, the remedies, etc. In this way, the report sought to bring together the experiences of developing the book, the description of the process, as well as the incorporation of excerpts from the stories, important to debate the stigma and discrimination of PLWHA over the years in Brazil.

## Methodology

The book 'What if it was with you? Lived Stories of Stigma and Discrimination in 40 Years of HIV/AIDS' is yet another action by the Associação Brasileira Interdisciplinar de AIDS (ABIA) to face stigma and discrimination associated with HIV and AIDS.

The book is part of the project 'Responding to the Stigma of HIV/AIDS in Brazil', of 2021, by ABIA in cooperation with the Ministry of Health, through the Department of Diseases, Chronic Conditions and Sexually Transmitted Infections of the Secretariat of Health Surveillance, and the United Nations Educational, Scientific and Cultural Organization (Unesco), which seeks to contribute to results management, improvement of governance and the national response to Sexually Transmitted Infections, HIV/AIDS and viral hepatitis, with a focus on prevention, health education and expansion of quality access to services provided to vulnerable populations<sup>8</sup>.

### Recruitment and selection

The project envisaged interviewing 10 to 12 People Living With HIV/AIDS, from different regions of Brazil, with the aim of exposing experiences of stigma, discrimination and prejudice, as well as confrontations and resistance.

To this end, a call was made via ABIA's social networks and institutional direct mail. All interested parties should get in touch via email, expressing their interest in telling their own story, safeguarding the right to anonymity.

In total, there were 15 volunteers, with a

first contact to explain the book and obtain information about the subject. Among the volunteers, because of the size defined for the book, 10 participants were selected, taking into account profiles that could bring different types of situations experienced, age groups, genders, races, sexual orientations and regions of origin/home, to try to show different aspects of living with HIV/AIDS in Brazil over the years.

### Interviews

Before conducting the interviews, all participants were informed about the nature of the project: A book with stories of People Living With HIV/AIDS.

After recruitment, five men and five women were chosen, living in the following places: Rio de Janeiro, São Paulo, Amazonas, Rio Grande do Sul, Paraíba and the Federal District, some with experiences in different parts of Brazil.

All participants signed a 'Content and Voice Use Authorization Term' (the interviews were conducted on video, but only the audio was downloaded from the Zoom platform) and had access to stories inspired by their lives, including the choice of real or fictional name in the story.

Based on the interviews, ten stories inspired by the lives of the interviewees were created, in a literary text format, containing situations such as the discovery of HIV, dreams, professions, in addition to the various occasions of sexual/racial prejudice, stigma and discrimination due to gender, sexuality, color and HIV. *Table 1* shows the names of the people in each tale, with their respective titles and profiles.

Table 1. Profile of the people interviewed for the construction of the book 'What if it was you? Lived Stories of Stigma and Discrimination in 40 Years of HIV/AIDS' - 2021

| Tale | Real or fictional name | Título do conto  | Perfil  |
|------|------------------------|--|---|
|      | Short story title      | Let's go, forward! Let's live!                                       | Cis woman, from Rio de Janeiro, retired history teacher, heterosexual, white, 60 years old, living with HIV for 20 years.   |
|      | Profile                | Paths: Riding with self-love   | Cis man, from Belford-Roxo, student and activist, homosexual, black, 31 years old, living with HIV for 7 years.   |
| 3.   | Isabella               | Resilient: capable of dreaming and rewriting her own story           | Cis woman, born in the interior of Rio de Janeiro, student, heterosexual, white, 24 years old, living with HIV since she was born through vertical transmission.            |
| 4.   | Alonzo                 | How can it have so much stigma: situations that freeze life          | Cis man, from Rio de Janeiro, nurse, bisexual, black, living in the United States, aged 39, living with HIV for 10 years.   |
| 5.   | Thaylla                | My story is not just mine: many Thayllas are born and die all around | Trans woman, from Rio de Janeiro, peer educator and activist, bisexual, black, 32 years old, living with HIV for 4 years.   |
| 6.   | Leonardo               | From Rio to São Paulo: the art of reinventing oneself                | Cis man, from Niteroi, English teacher, homosexual, black, living in São Paulo, aged 35, living with HIV for 11 years.  |
| 7.   | Vanessa                | Hard road to the dream: reminiscences, fights and smiles             | Cis woman, from Manaus, activist, heterosexual, with experiences in Rio de Janeiro, São Paulo and Joinville, aged 49, living with HIV for 30 years.                         |
| 8.   | Octávio                | Findings and missings: the art of a life in transformation           | Cis man, from Maranhão, professor, homosexual, resident of the Federal District, with experiences in the south of Brazil, white, 30 years old, living with HIV for 8 years. |
| 9.   | José                   | The storyteller: 'reversing' prejudices with information             | Cis man, from Paraíba, retired and activist, heterosexual, black, 58 years old, living with HIV for more than 20 years.   |
| 10.  | Silvia                 | What if it was you?  | Cis woman, activist, from Uruguay, heterosexual, white, living in Rio Grande do Sul since adolescence, aged 51, living with HIV for 30 years.                               |

Source: Own elaboration.

The interviews lasted from 80 to 180 minutes, following a semi-structured script with more than 30 questions, addressed to different situations, according to the interviewee's profile, in three axes: personal and sexual characteristics; HIV/AIDS; and experiences of stigma/discrimination/prejudice. The questionnaire was developed from the conceptual framework of life stories and social memory, which does not seek reports of an absolute truth and encompasses versions of feelings and events narrated by individuals from their memories, which can be individual or collective, also social or particular, in addition to experiences from the remembrance of the past<sup>9-12</sup>.

In the first part, the objective was to find out more about the interviewee, from childhood, through the discovery of sexuality, the existence of other chronic diseases, gender and color identification, even study, profession and place of residence. Also, if the person had any involvement with the social movement or any non-governmental organization.

To introduce the subject that was the motto for the project, some questions were always asked: 'For you, what is stigma? What is Prejudice? And what is discrimination?'. In the interviews, it was clear that there was no right or wrong answer, but a speech from a personal experience.

In the second part, came the first questions about the HIV infection, the time living with the virus, previous knowledge about the HIV/AIDS subject, the disclosure process – or secrecy – to friends and family, in addition to life in general with the HIV, including sexual life. It was important to know the context of the infection, if the person had information, if there were advances in medicine on the subject and if they had lived with People Living With HIV/AIDS before.

Finally, the interview addressed the most difficult circumstances: in which situations, in the interviewee's opinion, had he/she faced stigma, prejudice and/or discrimination; and, thus, investigate where they had occurred, in what situation, with which people, seeking to understand the feelings, reaction and impact on the participant's life.

The idea was to get to know the situations experienced, traumatizing or not, related to the experience of living with HIV, but also to know a little more about these people. Since there is a prejudice against HIV, present in different reports in the last four decades<sup>5,7</sup>, the attempt was to show who these people are behind the HIV stigma: mothers, fathers, workers, activists, with a whole life and other characteristics apart from the characteristic of carrying this virus. Discrimination would be a behavioral response to negative attitudes, being an effectuation of stigma and prejudice, that is, stigma and prejudice are considered the theory; and discrimination, the practice<sup>4</sup>.

Throughout the interview, the participant was always asked what had been the most traumatic experience, the most negatively striking, something difficult to forget, or something of great impact. Although there were several situations, the emphasis of the texts was exactly on those experiences highlighted by the interviewees.

Following the guideline of the script, during the interviews, subjects such as the right to secrecy, serodifferent or equal relationships and discovery/disclosure of the diagnosis, health care and care, as well as health policies and medical discoveries were addressed.

## In short stories: situations of stigma and discrimination

By itself, disclosing the diagnosis was not easy for many interviewees, and some have not even disclosed the diagnosis to the family even after years. In many situations, the right to secrecy was not respected, bringing moments of exposure of children of People Living With HIV/AIDS, teachers violating the trust of students, orphaned children with their confidentiality violated in the family, at school, etc.

*Because the stigma exists. And it doesn't have to be directly with you. It could be with an acquaintance. With a coworker. A patient. Silencing is the same. And this will also kill you little by little. (Tale Alonzo).*

*As a child living with HIV, [she] had her confidentiality violated from the beginning, because many people in the family knew. (Tale Isabella).*

*There was no secrecy. After trying to hide so much, everyone in the company knew, so suddenly. Without the slightest care. (Tale Silvia).*

Breaking the confidentiality of the diagnosis is recurrent among PLWHA, and the reports are permeated by 'gossip', when information about a person is transmitted to third parties, damaging the public image, either in the social environment or in health services, and still linked to so-called deviant behaviors<sup>13</sup>. Stigma goes beyond a negative mark and is connected to a social process in which PLWHA tend not to share their diagnosis<sup>13,14</sup>, whether with friends, family or health services. Thus, stigma and discrimination can harm both access to services and health care<sup>13</sup>. When the 'secret' is revealed, the stigmatized individual manages the tension generated around social contacts, faces prejudice, tends to isolate itself and even to withdraw from the social environment to be able to deal with the breach of confidentiality of the diagnosis, while the

one that reveals the diagnosis manages its failure around the disclosure of confidential information<sup>15</sup>.

Several cases of health professionals with less than humanized attitudes were also cited, or even denying care to People Living With HIV/AIDS, using various excuses.

*The dentist simply made up several excuses for not doing the wisdom tooth extraction after she found out. That's right: even a lack of water the woman invented. (Tale Sandra).*

*I was instructed to disclose the diagnosis to the health professionals that cared for me. And I've suffered discrimination a few times... (Tale Isabella).*

*In an impersonal, practically violent way, the doctor spilled information about the treatment, because 'it was only possible to 'worry' from then on'. The situation was so traumatic, he almost gave up on the treatment. (Tale by Jean Vinícius).*

It should be emphasized that several different situations of disrespect for pregnant women living with HIV/AIDS emerged, also exposing these women's children.

*Even worse, the exposure of my diagnosis. My daughter's exposure. That's right, my daughter's Health Booklet came written, in bold letters, with a red pen: 'Child born to an HIV+ mother'. (Tale Vanessa).*

The fear of prejudice or even of infecting the child at birth can be a motivator for women living with HIV/AIDS to postpone motherhood, and in Brazil, there is the fear of being a revealer of the serology or a constant reminder of the diagnosis<sup>16</sup>. The lack of information about HIV prevention and treatment technologies can generate stigma and discrimination in the social environment, therefore, it would be important to keep health professionals up-to-date on biomedical advances, in order not to issue attitudes of discrimination, in addition to constant vigilance so that religious and

moral beliefs do not encourage such attitudes. Therefore, it is necessary to work with intervention projects, mainly on the moralistic conception around the HIV infection that has been seen since the beginning of the epidemic, which can segregate infected people as 'guilty' or 'innocent'<sup>17</sup>. Judgment is carried out by HIV infection itself, for which people can be considered 'guilty' just for having the virus and thus being discriminated against in health services, as reported by participants in the book.

The 'moral careers' are related to the processes by which individuals who perceive themselves as 'normal' in society discredit those who have a mark<sup>3</sup>. In the study with an approach based on Goffman's concept, four patterns of stigma were identified from the life stories of children/adolescents and which can also be identified in the interviews in the book, such as: innate stigma (socialized as sick people); stigmatization kept in secret (unplanned HIV disclosure); late stigmatization (HIV test in adolescence); and raised in social institutions<sup>18</sup>.

In the interviews, prejudice and attempts to restrict motherhood and sexual freedom for women with HIV were also mentioned.

*When I started treatment, the discussion was: people with HIV cannot have more children. Or you can't breastfeed. Why not? And the desires, the pleasures? HIV is not a problem for the 'carrier', even more so today. (Tale Sandra).*

*'You're going to have to stop this'. That was his mother's phrase when she found out about dating. 'If you become pregnant, you can put a child at risk'. Her idea was that I should never have sex again. (Tale Vanessa).*

Thus, the notion of 'risk' was also used for women who wanted to become mothers at the beginning of the epidemic. Nowadays, there is progress in the debate on the sexual and reproductive rights of those living with HIV/AIDS, and it is important to have access to information and an understanding of their rights, so



that they can take control of their own bodies in decision-making about motherhood<sup>19</sup>.

Although positive welcoming experiences have emerged, various situations of stigma and discrimination with family, partners or friends were also narrated:

*Everything was going well until, before the sexual intercourse, he decided to tell him about the diagnosis. The guy just ran away, stopped answering his calls and disappeared. He didn't even want to talk. (Tale by Jean Vinícius).*

*He hadn't even finished telling and his boyfriend had already lit a cigarette, opened his beer, with a lot of irritation and anxiety. 'You passed it on to me, now my life is ruined. And my family has no money. What am I going to do?'. (Tale Octavio).*

*'Pranks' with the positive diagnosis. 'Pranks' with the curly hair of others. 'Pranks' of calling someone a monkey. And even veiled looks and comments. Even if not conscious, or not assumed as racism or discrimination, there are many offensive and annoying situations. (Taylla Tale).*

*'How could you let that happen, with so much knowledge?'. 'How can you be such an idiot, having so many condoms around you?'. Phrases that echoed in Alonzo's head for years. Phrases uttered precisely by an experienced person. A person from whom I expected acceptance. A beloved professor at the college where he worked. (Tale Alonzo).*

The interviewees' reports also brought several moments of anguish and fear: the fear of not being able to work due to the diagnosis, the loss of a job due to its disclosure and all situations of exposure due to breach of confidentiality.

*The manager found out about my doctor's appointment and kept insisting to know what the problem was. We always talked, and I ended up telling. And I ended up fired, once again, the next day, via Human Resources. (Tale Leonardo).*

*The firing came after maternity leave. Even before that, I had already heard rumors that co-workers had been warned: 'Don't drink chimarrão with her'. Information about the diagnosis had leaked at the company. (Tale Silvia).*

*I know more than 50 people with HIV here who can't find a job. Only if they don't know, but if it gets back to someone at work, people get fired soon. (Tale José).*

Breaking the confidentiality of the diagnosis at work is considered a violation of the protective legislation for PLWHA in the work environment in Brazil, especially Law No. 12,984/2014, which prohibits: denying employment; exonerate or dismiss; segregate in the work environment; and disseminate the serology<sup>20</sup>. Another piece of legislation that protects the breach of diagnostic secrecy is Law n° 14,289/2022, which makes the confidentiality of some diseases, such as HIV, mandatory in the workplace<sup>21</sup>. Both laws also protect PLWHA from discrimination in the health care setting. There is also pressure from employers for PLWHA to resign when they discover their HIV status; or even dismissal allegedly for other reasons, without the record of compromising conversations; therefore, it is difficult to prove discrimination in the courts, in addition to obstacles in the reintegration of these people in the labor market<sup>6</sup>.

In many reports, people had not even made the disclosure to friends, family and partners, being a constant fear, in order to not suffer. When done, voluntarily or not, in many moments, people faced negative stereotypes and adverse reactions. On the other hand, despite mentioning many of these comments and negative situations related to their own diagnoses, the participants did not perceive behavioral changes in the lives of people who had negative reactions, to prevent possible self-infection.

*Knowing the diagnosis, many people welcomed it. Some didn't believe him: 'You are such a handsome*

*black man'. And others discriminated against him: 'If he takes a dose here, I'll break the glass'. (Tale José).*

*My neighbor, evangelical, married for over 10 years, only had sex with her husband and without a condom. She discovered her diagnosis and his, who had sex without a condom outside of marriage. And I have many other friends who say the same, they don't go out with a person with HIV, even if the guy is undergoing treatment, but they go out clubbing and have sex with an unknown partner, without a condom. (Tale Leonardo).*

The moral judgment around HIV usually falls on the other, and people close to the interviewees never bothered to reflect on their own sexual relations that could also cause infection by the virus. Community participation would be essential in creating strategies aimed at overcoming obstacles, to deal with the stigma of AIDS, especially with the promotion of human rights and with important changes, linked to legislation and discriminatory practices<sup>18</sup>. In Brazil, as discussed, there are advances around the protective legislation for PLWHA, but the problem lies in its application.

Exactly because of the moral judgment, there were often direct associations, with a lot of negative charge, between sexuality, sexual orientation and HIV:

*To make matters worse, everyone learned about a college boy's diagnosis: positive for HIV. And the boy ended up leaving the course. There was not much reception, on the contrary, a lot of misinformation and discrimination. That guy was Octávio's ex-boyfriend and the gossip started. Hallway stories. (Tale Octavio).*

*It was then that the 'question of being gay' arose, even though she heard from her stepfather that being gay attracts 'bad things', such as the HIV virus. (Tale Taylla).*

In addition to the initial scope, in the stories of the participants, other markers and cross-cutting themes emerged, such as: sexual

prejudice; sexuality; rape; genre; xenophobia, transphobia and LGBTQIA+ violence; mental suffering; racism, moral harassment, labor and legal struggles; sexual repression and false moralism; religious fanaticism; activism; maternity; suicide; ableism; deficiency; and sequelae of opportunistic infections in people with HIV.

Despite all the situations faced, in many speeches stood out statements about reinvention, learning, re-signification of one's own life, among other ways of dealing with receiving the diagnosis and the challenges inherent in living with HIV.

Many interviewees mentioned the fundamental nature of involvement with the social movement, in order to learn how to deal with the diagnosis and related situations. In the same way, the act of being able to talk about the subject freely, in interviews and in activism, was said to be a true 'catharsis', which helped to face one's own life.

*Nobody wants HIV! The name reinforces the issue of the risk group, which only have HIV if they want it: that's a lie. What interests me is that I have this 'stuff' and I want to treat myself. It is the treatment that makes the difference. (Tale Sandra).*

*And it was cool to meet an activist, it opened my mind. I saw that madness of him fighting for the lives of people with HIV; my place was that. (Tale José).*

*Over the course of six years, Jean has been involved with various social movements, including indigenous ones, and has traveled and met many different people and realities. He understood that he needed to give another meaning to his experiences to try to build a political journey, with issues developed in a more comprehensive way, thinking about racism, the right to health and how gender, sexuality and serology issues are allocated. (Tale by Jean Vinícius).*

*HIV is already part of my story today. The important thing is that this is part of life, not a death sentence. (Tale Alonzo).*



## Texts and pictures

To facilitate reading, there was an initial prediction that, as far as possible, the texts of each story should not be too long, so as not to tire the reader and instigate other readings. Furthermore, short texts could allow isolated or consecutive readings.

Likewise, there was the intention to add imagery value, that is, to include visual resources, with the aim of arousing curiosity and attention to the book. Initially, the idea was that beautiful drawings of each character would be made, also related, in some way, with the graphic design of the book. However, already in the search for illustrators, the option for an illustrator who represented the characters through engravings became clear, given their imaginative and subjective potential.

After carrying out the first three interviews, the author of the texts in the book listened to all the interviews again, repeatedly, to organize the narratives presented, highlighting topics expected in the making of the interview script (such as childhood, sexuality, age group, type of situation experienced, etc.), topics brought up by the interviewees (side effects of medication, suicide attempts, etc.) and all the situations considered outstanding by the interviewees, positive and negative. In addition, the method of organizing the interviews into topics followed in the composition of all the texts in the book.

As most of the interviews had been done online with video, but with audio recording only, there was already an observational record of many non-verbal elements associated with each detail: watery eyes, pauses and silences, trembling voices, crying, tones of different voices.

In addition, the interviewee itself also brought his/her characteristics: a more detailed narrative, funny or activism stories, specific details, description of emotions, resistances, catharses, etc.

All these verbal and non-verbal elements of the interviews were taken into account to present the central character, to define the speed of the narrative, as well as its length and level of detail, to really bring out a 'character' that provided an idea of the comprehensive and special nature of each of these interviewees, even if briefly in some pages. The more personal and detailed the interview, the more subjective the text, to include emotions, phrases and impressions of the interview and the interviewees.

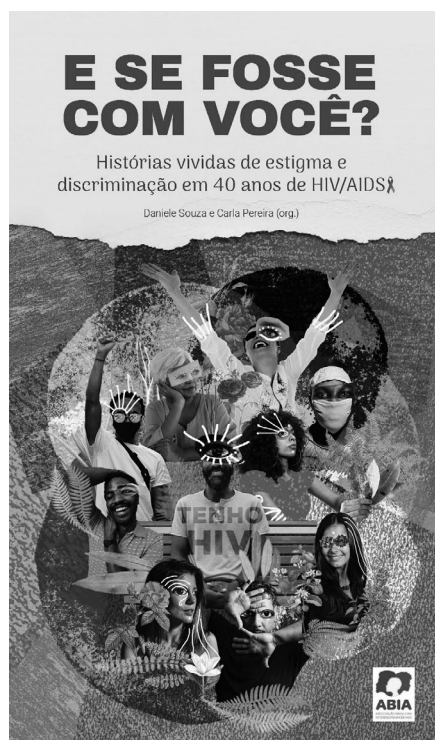
After writing each text, it was revised by the interviewers, by members of the ABIA team, as well as passed on to the interviewee, in order to correct possible errors and even to adjust to the guidelines of the social movement, to avoid terms considered stigmatizing. In general, the interviewees requested few revisions, but those who proposed alterations or omissions in content were complied with.

During this review process, there was a concern to use quotation marks for words that are more stigmatizing, although they are commonplace in society. Care was also taken to add notes for certain terms mentioned, related to treatment, expressions and concepts – such as PrEP, undetectable, cis –, with the aim of clarifying doubts and providing additional information to the interested reader.

For the pictures, there was the same concern: to raise different ideas linked to the character. Therefore, meetings were held with the illustrator, to provide subjective and objective details, characterizing each character and suggesting crucial elements – according to the interviews: as being from the health area, a storyteller, etc. *Figure 1* shows the cover of the book, bringing together the illustrations of the stories based on open access photographs.

When all the stories were written, the text also went through a final review by ABIA's project coordination and by Unesco's review for technical approval.

Figure 1. Cover\* of the book 'What if it was you? Lived Stories of Stigma and Discrimination in 40 Years of HIV/AIDS' - 2021



Source: Souza and Pereira<sup>22</sup>.

\*Illustrator: Hannah 23.

## Launch and distribution

On the occasion of World AIDS Day (December 1st), the book 'What if it was you? Lived stories of stigma and discrimination in 40 years of HIV/AIDS', was launched on December 2nd, 2021, during the ABIA seminar 'Remaking prevention'.

The activity had the participation of the project developers, the coordinator of the project 'Responding to the Stigma of HIV/AIDS in Brazil' and the illustrator, in addition to interviewees who had already chosen not to keep their diagnosis confidential.

On the occasion, the book was presented, as well as other experiences were shared, by the participants of the table or by the public present, in the online launch (due to the Covid-19 pandemic). After this, the book was made

available on the ABIA website and disseminated among peers.

Book participants received copies for dissemination, as well as several books were distributed to libraries, civil society organizations, universities, among other partners to replicate the work, which had an initial print run of 2,000 copies.

The interviews had a direct impact on the members of the project, with many reflections on what was said. Sleepless nights and anguish in the face of so much injustice, as well as an inspiration due to the resilience of the interviewees. In addition, the people interviewed themselves reflected on things that they had never stopped to think about living with HIV/AIDS.

There were several uses of the book. For example, interviewee Thaylla distributed

the book at a workshop for trans/trans-vestite women. The book was also used in an extension course that addressed human rights in health (Federal University of Rio de Janeiro – UFRJ, Public Defender’s Office-RJ, among other partners), and will be part of the Distance Learning Course of the Oswaldo Cruz Foundation (FIOCRUZ) about stigma and discrimination in certain diseases.

## Final considerations

In total, there were 15 volunteers, among other expressions of interest in participating in the project. From there, ten interviews were carried out that generated ten stories, with people from or living in the five regions of Brazil.

In selecting the interviewees, priority was given to different sociodemographic contexts, situations and experiences of stigma, prejudice and discrimination, in addition to various personal characteristics of the interviewees.

All the reports of people with HIV brought experiences of stigma, discrimination and prejudice, in different areas: family, among friends, lovers, at work, with health professionals and even in religious and social areas – something that reveals the pressing and current character of actions to face the epidemic of stigma and discrimination, beyond the existence of HIV itself.

In the interview and in the post-launch, some interviewees narrated the feeling of confrontation when remembering and facing the memories with situations of stigma, prejudice and discrimination, already with an activism perspective, understanding the situations experienced. Also, as a surprise, one of the interviewees used the story in the book to tell

the family about the diagnosis, fortunately having a positive reaction.

Thus, both the interviews and the book launch event provided situations for People Living With HIV/AIDS to have a space for dialogue and expression of their own feelings, experiences and concerns regarding life with the diagnosis.

Even more significantly, the experience of making the book also provided the opportunity for the creators and project participants to learn a lot about the experiences of these people and the ways of coping.

Therefore, the conclusion is that the book can indeed enhance the sharing of these experiences – negative and positive – of People Living With HIV/AIDS and encourage empathy and solidarity around the group, especially due to the expanded possibility of dissemination, in electronic and academic media.

## Acknowledgments

The Associação Brasileira Interdisciplinar de AIDS (ABIA), for the opportunity to develop the book.

## Collaborators

Souza D (0000-0002-5870-3281)\* was responsible for the creation and writing of the article. Pereira C (0000-0003-4692-0665)\* helped with writing and making the table and figure presented in the article. Raxach J (0000-0002-9460-2154)\* participated in the critical review of the text and final approval. ■

---

\*Orcid (Open Researcher and Contributor ID).

## References

1. Brasil. Ministério da Saúde, Secretaria de Vigilância em Saúde. Boletim Epidemiológico. 2021 [acesso em 2022 abr 8]; (esp):1-71. Disponível em: <https://www.gov.br/saude/pt-br/centrais-de-conteudo/publicacoes/boletins/epidemiologicos/especiais/2021/boletim-epidemiologico-especial-hiv-aids-2021.pdf>.
2. Nações Unidas. Nova variante de alta transmissão do HIV afeta em dobro o sistema imunológico. ONU News. 2022 fev 7. [acesso em 2022 abr 8]. Disponível em: <https://news.un.org/pt/story/2022/02/1779102>.
3. Gesesew HA, Gebremedhin AT, Demissie TD, et al. Significant association between perceived HIV related stigma and late presentation for HIV/AIDS care in low and middle-income countries: A systematic review and meta-analysis. *PLoS One*. 2017 [acesso em 2022 abr 8]; 12(3):e0173928. Disponível em: <https://pubmed.ncbi.nlm.nih.gov/28358828/>.
4. Goffman E. Estigma: Notas sobre a manipulação da identidade deteriorada. Rio de Janeiro: LTC; 2013.
5. Parker R. Interseções entre Estigma, Preconceito e Discriminação na Saúde Pública. In: Monteiro S, Vilela W, organizadores. Estigma e Saúde. Rio de Janeiro: Fiocruz; 2013. p. 25-46.
6. Bezabhe WM, Chalmers L, Bereznicki LR, et al. Barriers and Facilitators of Adherence to Antiretroviral Drug Therapy and Retention in Care among Adult HIV-Positive Patients: a Qualitative Study from Ethiopia. *PLoS One*. 2014 [acesso em 2022 abr 8]; 9(5):e97353. Disponível em: <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0097353>.
7. Pereira CRP, Szwarcwald CL, Damacena GN. A discriminação de Pessoas Vivendo com HIV/AIDS no Trabalho: Uma Análise Quantitativa e Qualitativa. *P2P Inovação*. 2019 [acesso em 2022 abr 8]; 6(1):60-82. Disponível em: <https://revista.ibict.br/p2p/article/view/4832>.
8. Associação Brasileira Interdisciplinar de Aids. Plano de trabalho do projeto: 'Respondendo ao Estigma ao HIV/AIDS no Brasil'. Rio de Janeiro: ABIA; 2021.
9. Benjamin W. Obras escolhidas I: magia e técnica, arte e política. São Paulo: Brasiliense; 1993.
10. Halbwachs M. A memória coletiva. São Paulo: Vértice; 1990.
11. Pollak M. Memória, Esquecimento, Silêncio. *Estudos Históricos*. 1989; 2(3):3-15.
12. Silva VP, Barros DD. Método história oral de vida: contribuições para a pesquisa qualitativa em terapia ocupacional. *Rev. Ter. Ocup. Univ*. 2010 [acesso em 2022 abr 8]; 21(1):68-73. Disponível em: <https://doi.org/10.11606/issn.2238-6149.v21i1p68-73>.
13. Sciarotta D, Melo EA, Damião JJ, et al. O 'segredo' sobre o diagnóstico de HIV/Aids na Atenção Primária à Saúde. *Interface (Botucatu)*. 2021 [acesso em 2022 abr 8]; 25:e200878. Disponível em: <https://www.scielo.org/article/icse/2021.v25/e200878/>.
14. Parker R. Estigmas do HIV/Aids: novas identidades e tratamentos em permanentes sistemas de exclusão. *Rev Eletron Comum Inf Inov Saúde*. 2019 [acesso em 2022 abr 8]; 13(3):618-33. Disponível em: <https://www.reciis.icict.fiocruz.br/index.php/reciis/article/view/1922/2293>.
15. Judgeo N, Moalusi KP. My secret: The social meaning of HIV/AIDS stigma. *SAHARA J*. 2014 [acesso em 2022 abr 9]; 11(1):76-83. Disponível em: <https://pubmed.ncbi.nlm.nih.gov/24980478/>.
16. Silva CB, Motta MGC, Bellenzani R. Maternidade e HIV: desejo reprodutivo, sentimentos ambivalentes e cuidado (não) ofertado. *Rev Bras Enferm*. 2019 [acesso em 2022 abr 9]; 72(5):1446-57. Disponível em: <https://www.scielo.br/j/reben/a/cMKxwBskGW7fJLX5xLftzCT/?lang=pt&format=pdf>.
17. Mott L. A Transmissão Dolorosa do HIV-Aids: relatos na imprensa brasileira. *Impulso: Rev Ciênc Soc Human*. 2002; 13(32):157-174.

18. Cruz MLS, Bastos FI, Darmont M, et al. The 'moral career' of perinatally HIV-infected children: revisiting Goffman's concept. *AIDS Care*. 2015 [acesso em 2022 abr 9]; 27(1):6-9. Disponível em: <https://pubmed.ncbi.nlm.nih.gov/25054808/>.
19. Carvalho JMR, Monteiro SS. Visões e práticas de mulheres vivendo com HIV/aids sobre reprodução, sexualidade e direitos. *Cad. Saúde Pública*. 2021 [acesso em 2022 abr 8]; 37(6):1-11. Disponível em: <https://scielosp.org/article/csp/2021.v37n6/e00169720/>.
20. Brasil. Lei nº 12.984, de 2 de junho de 2014. Define o crime de discriminação dos portadores do vírus da imunodeficiência humana (HIV) e doentes de aids. *Diário Oficial da União*. 2 Jun 2014.
21. Brasil. Lei nº 14.289, de 03 de janeiro de 2022. Torna obrigatória a preservação do sigilo sobre a condição de pessoa que vive com infecção pelos vírus da imunodeficiência humana (HIV) e das hepatites crônicas (HBV e HCV) e de pessoa com hanseníase e com tuberculose, nos casos que estabelece; e altera a Lei nº 6.259, de 30 de outubro de 1975. *Diário Oficial da União*. 3 Jan 2022.
22. Souza D, Pereira C, organizadoras. *E se fosse com você: histórias vividas de estigma e discriminação em 40 anos de HIV/Aids*. Rio de Janeiro: ABIA; 2021. [acesso em 2022 abr 8]. Disponível em: [https://abiaids.org.br/wp-content/uploads/2021/12/Livro-PDF\\_Abiaids\\_ESeFosseComVoce\\_livroCompleto\\_site.pdf](https://abiaids.org.br/wp-content/uploads/2021/12/Livro-PDF_Abiaids_ESeFosseComVoce_livroCompleto_site.pdf).

---

Received on 03/15/2022

Approved on 09/20/2022

Conflict of interests: non-existent

Financial support: United Nations Educational, Scientific and Cultural Organization (Unesco)