


No “OLSW” in youth and retirement pension at risk: an autoethnography on the activism for the rights of people living with HIV/AIDS¹

Sem “Loas” na juventude e aposentadoria em risco:


uma autoetnografia sobre o ativismo por direitos em HIV/aids

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Abstract

This article presents the narratives of young people born with HIV told in chatting circles of a Working Group on Vertical Transmission of HIV and Youth. The themes relate to employability and social benefits, as well as the loss of retirement pensions by people living with HIV/AIDS (PLHA) from 2016 to 2019. Based on the concept of intersectionality, this qualitative research consists of the autoethnography of a Black intersex travesti activist and of a document analysis of minutes, news, meeting memories, personal notes, and legislations.

Keywords: Intersectionality; HIV; Activism; Rights; Employability.

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¹ The term “Loas” in the Portuguese title is a wordplay with the acronym for Lei Orgânica de Assistência Social (Organic Law of Social Welfare), known in Brazil as “Loas”, which in Portuguese is also a word meaning “praise”, “esteem” and “sympathy”

Resumo

Este artigo busca contar as narrativas de jovens que nasceram com HIV apresentadas em rodas de conversa de um Grupo de Trabalho sobre Transmissão Vertical do HIV e Juventudes. Os temas abordados dizem respeito à empregabilidade e benefícios sociais, bem como analisam a perda de aposentadorias por Pessoas Vivendo com HIV/aids (PVHA) no período de 2016 a 2019. O método utilizado para esta pesquisa qualitativa é a autoetnografia de uma ativista travesti negra e intersexo, além da análise documental de atas, notícias, memórias de reuniões, anotações pessoais e legislações, tendo como escolha conceitual de análise a interseccionalidade.

Palavras-chave: Interseccionalidade; HIV; Ativismo; Direitos; Empregabilidade.

Introduction

HIV is the human immunodeficiency virus, which causes AIDS (acquired immunodeficiency syndrome), a pathology that attacks the immune system, which is in charge of defending the body from diseases. That is what the web portal of the Department of Chronic Diseases and Sexually Transmitted Infections (IST) of the Brazilian Ministry of Health reports. In Brazil, the response to the epidemic began in 1983, first in São Paulo, with the creation of the first specialized service for AIDS care, called Programa Estadual de DST²/Aids de São Paulo the state STD Program/ Aids of São Paulo - according to data from the web portal of the Health Ministry. Then, the Brazilian AIDS Program was instituted.

In 1996, the AIDS epidemic underwent a transformation in Brazil. With the arrival of antiretroviral therapy (ART)³ and universal access to treatment available to all as persons living with HIV/AIDS (PLWHA), they achieved a much longer life expectancy. I myself have been using these drugs since 2014, so I consider myself to be someone with chronic infection. Thus, PLWHAS stopped being retired or receiving Invalidity/Disability Allowance (BPC)⁴ of the Organic Law of Social Welfare (OLSW), which are rights and benefits granted by the welfare system, since they were regarded as being fit for work.

Even with all this progress in the implementation of treatment by the National Health System (SUS), there are still racial and gender inequalities that have an impact the epidemic in the country. Regarding race, the data presented by the Ministry of Health in an epidemiological report from 2020 show that, out of a total of 342,459 cases reported in the Notifiable Diseases Information System (Sinan) between 2007 and June 2020, 50.7% occurred among black persons (blacks, 10.7%, and browns, 40.0%) and 40.1% among whites. Among men, 41.7% of cases

2 STD: Sexually Transmitted Disease, a term that has gradually been replaced by Sexually Transmitted Infections (STIs).

3 ART, commonly known as “drug cocktails”, consists of drugs that suppress the amount of HIV in the body and prevent HIV from developing symptoms and culminating in the AIDS stage (Tancredi, 2010).

4 It is a social assistance benefit, amounting to a minimum monthly wage, paid to elderly people (aged 65 years or older) or persons of any age with disabilities that do not allow them to provide for themselves. To be eligible for it, one must prove having per capita family income below 1/4 of a minimum wage. One must also undergo medical and social evaluation by the National Institute of Social Security (INSS). Social security deductions are waived as this is a social assistance benefit. BPC beneficiaries are also eligible for discounts on electricity bills (Social Energy Fee) (Brazil, 2019b).

occurred among whites and 49.2% among blacks (9.8% black and 39.4% brown men); among women, the inequality in infection between whites and blacks is greater: 36.6% of cases occurred among white women and 54.3% among black women-12.9% black and 41.4% brown women (Brazil, 2020).

Regarding AIDS mortality, this racial and gender inequity is greater. Out of the 10,565 deaths reported in 2019, 61.7% were black people, and black women had the highest percentage: 62.1% of women's deaths. The report also informs us that between 2009 and 2019, there was a decrease of 21.0% in the proportion of deaths of white people and an increase of 19.3% in the proportion of deaths of black people. These data show us that black people (particularly black women) are more vulnerable to the epidemic.

Furthermore, the issue of work and income should also be taken into account in the epidemic. It is estimated that 60 to 70% of the population living with HIV is outside the formal labor market, according to information released at an interministerial meeting in 2016 between the Ministries of Health, Labor and Welfare (Brazil, 2016). In the last four years, welfare and social security have become important political demands for PLWHA due to the withdrawal of the disability benefit for adolescents and young adults (particularly those born with HIV) and the withdrawal of pensions for old people with HIV who retired before anti-HIV therapy was available.

In 2016, a fraud in the verification process was put in place to reduce spending on social security. In this process, PLWHAS who had relied on disability benefits and pensions, some of them for more than two decades, were "un-retired" by the assessment that they were fit for work (rights of people..., 2019). At the same time, young people and children born with HIV, although eligible to receive the disability benefit, faced growing challenges to obtain it due to the benefit review

process, and those who already were recipients faced the insecurity of losing it.

I followed some of these struggles as an activist with the AIDS social movement, of which two are highlighted in this article: young beneficiaries of the disability benefit, participants in the Working Group (WG) of Vertical Transmission of HIV⁵ and Youth groups of the Positive São Paulo Youth Network (RJSP+) and the São Paulo Training Reference Center (CRT) for STD / AIDS; and in the cases of un-retirement, through the Loka de Efavirenz^{6,7} collective, of which I am a member. This collective received several requests for help to advertise political acts, petitions and mobilizations of cyber activism.

In this article, I attempt to vocalize these struggles from my perspective as an activist, socialist, black, transvestite, intersex person living with HIV/AIDS and also a public health worker and researcher. I will give a brief account, with an ethnographic treatment of my wanderings and the accounts I witnessed in HIV/AIDS activism related to this topic and, with the help of spontaneous, unintentional records, reports of events, minutes, notes written on brown paper by young people in chat circles, notes in my personal notebooks, conversations with people with whom I lived at the time and who are still very close to me and, obviously, my own memory.

In addition to this introduction, in the first part of the text I explore my conceptual and methodological choices with the help of ethnography and the concept of intersectionality applied to the AIDS epidemic. After that, the text moves on to the analysis of the perceptions of young people (aged 18 to 29 years) with whom I worked as an activist between 2016 and 2019, and their paths with the AIDS epidemic and relationships with work, employment and income; at the end of this section, I explain what I witness regarding the loss of pensions by some PLWHA.

5 The term "vertical transmission" refers to HIV contagion at the moment of childbirth, but it commonly also includes PLWHA who were infected in childhood. To refer to this population, we can also use the expression "people born with HIV"

6 Available at: <https://www.facebook.com/LokadeEfavirenz/>. Access on: April 8, 2020.

7 Efavirenz is an antiretroviral drug which was a protocol medication for anti-HIV treatment shortly after the diagnosis of most Brazilian PLWHA until early 2019. Its use was suspended due to side effects related to the nervous system and psychic suffering in some patients. (TESTA et. la., 2009).

Methodological and conceptual choices

This is the writing of an experience marked by oppressions of gender, race and social class, and also of political activism, especially in social movements and socialist branches of left-wing parties. For this account, I freely use references that come from: (1) ethnography and autoethnography (Ellis; Adams; Bochner, 2011; Geertz, 2008; Williams, 2011); (2) from the perspective of intersectionality, born of black feminism and the analysis that markers of race, gender and social class are crucial and inseparable for understanding social dynamics (Collins, 2017; Davis, 2017; Gonzalez, 1979; Hirata, 2014); and (3) the stigma of AIDS (Goffman, 1981; Parker; Aggleton, 2001).

According to Geertz (1973), ethnography is a dense, detailed description of a culture based on the experience and, above all, the interpretation of one who is in the field as a participant observer. The anthropologist has a semiotic notion of culture; in this sense, **ethnography** as a dense interpretative description is, therefore, “something built, something modeled” by the anthropologist, a kind of fiction, especially when one speaks of a culture of which o(a) researcher is not a native.

Conversely, autoethnography, according to Ellis, Adams and Bochner (2011), besides seeking a dense description because it is also ethnography, also seeks to elaborate aesthetic and evocative descriptions of personal and interpersonal experience in the field. This can be achieved through cultural experience in a particular group or territory, depicted by field notes, interviews, artifacts and personal memories. Subsequently, all of that is communicated through an original and personal narrative. In this narrative story, the researcher is also a character and is part of the plot with his personal experience and feelings; in a way, he affects and is affected by the culture that he reports on, whether or not he is a “native”. For this reason, I opted for autoethnography as a method to tell this experience.

Autoethnography is, thus, the combination of the characteristics of autobiography and ethnography; as such, it is not enough for the ethnographer to just tell his personal experiences in the field: he also has to analyze them culturally (and historically). In the meantime, we can say that autoethnography is a

process (of investigation and analysis) and at the same time a product (of narration of the author’s experiences and theoretical choices) (Ellis; Adams; Bochner, 2011).

I also argue as a background that within the culture there are also disputes over power and domination, predominantly in capitalist societies. That is what Raymond Williams (2011) points out by stating that there is a hegemony of the dominant sectors of society (especially the economic elites) in the structure, in the institutions and in the various instruments of socialization that act in the formation of customs, common sense, signs and symbols, with the goal of perpetuating the *status quo* - social classes and power structures. However, this relationship is not static.

In my case, I was a “native” to some extent because I live with HIV, but besides belonging to the population that had sexually transmitted HIV and having other relationships with the epidemic, I did not participate in chat circles with the purpose of doing ethnography. I took the notes for report, minutes and personal use, to be used only in the social movement for creating content on social media of the RJSP+ and to think about the master’s degree project that I was going to submit in the following year, on the employability of black people living with HIV/AIDS. Therefore, autoethnography emerged later, by “accident”, because participant observation was not done as a researcher, but instead as a facilitator of those chat circles; now, I deepen those experiences from my memory, notes written in my notebook and public documents.

Autoethnography, according to Magalhães (2018), allows the researcher to involve and transpose their emotional experiences into their study. Ethnography, which consists in the researcher’s participant observation of the daily life of the subjects and the universe studied, should, for this author, be an autoethnography because there is no way of analyzing the culture of one people, the other or even life itself (if that is the subject of the study) without being influenced by the researcher’s perception, his life experience or worldview. “While positivist research attempts to be impersonal [...], qualitative autoethnographic research underlines the importance of the researcher’s personal

experience as a form of knowledge construction in sociocultural studies [...]” (Magalhães, 2018).

Versiani (2002) says that autoethnography is “a useful conceptual alternative to cultural researchers concerned with overcoming [...] the procedural and intersubjective nature of these discursive constructions” (P. 68-71), a conduct of showing the ethnographer’s own point of view and interpretation of the culture and the events, avoiding essentialism and universalism in creating an “ideal subject” and a neutral scientist at the same time, standing at a distance from the reality of the other who constitutes the “study object”.

Intersectionality

Besides the biological impact that HIV and AIDS can cause, if the infected person is not given adequate treatment and minimally dignified living conditions, social implications may result from the stigma and discrimination. One of these implications can be described as what several authors call the construction of the identity of the patient’s stigmatized body, which proves a potential (criminalized) vector of an incurable disease, in the case of AIDS. Such prejudice can meddle with issues of sexuality, racism, social inequality and sexism (Ferreira; Figueiredo, 2006; Perrusi; Franch, 2012).

Hirata highlights the pioneering use of the *stricto sensu* term “intersectionality” in the works of Kimberlé Crenshaw. The term encompasses the analysis of the relationship between oppressions of gender, race and social class, or of social distinction, and it dates back “[...] to the late 1970s movement known as Black Feminism [...], whose collective criticism turned radically against white, middle-class, heteronormative feminism” (Hirata, 2014, P.62).

Following the path pointed out by Helena Hirata regarding black feminism, we can highlight the presence of intersectionality in Angela Davis’s work even before this term was used to define such a form of analysis, addressing the interrelationship between exploitation in labor and class relations with different oppressions, especially racism and sexism. This idea is inscribed in the very title of the book - *Women, Race and Class* -, originally published in 1981, thus the criticism of the election

of only one oppression, circumscribed to a specific reality (in this case, sexism faced by white middle-class women), to universalize the entire category of “woman”, ignoring the realities of the black population and what Davis calls ethnic minorities.

Lélia Gonzalez, in turn, addressed this issue in the Brazilian context. According to the author, there is a racial and gender division in labor in Brazil (Gonzalez, 1979) that results in the best positions being occupied by white men, while the black population is assigned the base of pyramid: precarious jobs or downright unemployment. Black women suffer even more in such a situation, in a threefold oppression.

Patricia Hill Collins (2017) understands intersectionality as a category that synthesizes race, class and gender into a single concept, which cannot, however, be only analytical. The author believes in a political practice of intersectionality that aims at social justice and serves as an instrument for collective and individual emancipation. In this perspective, his biggest criticisms are what he calls “imperfect translations of the term”, emerged in social movements, by the academia, which tried, and still does, to portray intersectionality as something adaptable to neoliberalism or as an analytical, almost contemplative, perspective detached from politics. Analyzing the social entirety of oppression in a capitalist system must make a contribution for social transformation. In this respect, Collins, who I consider to be more moderate, agrees with Davis, who is openly communist: intersectionality is essentially an analysis that serves the struggle for freedom.

Why talk about all this when addressing the issue of AIDS? It is possible to find clues to such motives in the book *Women, Culture and Politics*, originally published in 1989, in which Angela Davis points out that black and Latino women are “victims of AIDS in disproportionately large numbers” (2011, p.13). The author defends the emergency of creating a financial fund to fight the disease (at the time still with few scientific progress), in addition including this demand in the agenda of the black women’s movement and the total opposition to “all instances of repressive mandatory AIDS testing and quarantining, as well as homophobic manipulations of the AIDS crisis” (Davis, 2011, p.13).

We should emphasize here the understanding of Verena Stolcke (1991) that the interconnection of race, gender and class in capitalist bourgeois society cannot be taken as an “addition” or “overlap” of oppressions of ideological and economic bias, but rather as concomitant and simultaneous structures that feed each other. One cannot think about the structuring of working classes (and their more or less precarious fractions) without analyzing the history of racialization, especially of the former colonies, as well as the role of gender for the social reproduction of life - and consequently of work. Furthermore, for a system of social inequality, it is crucial that such economic inequities be legitimized by biologizing ideologies, either through the idea of “race” as a category of inferiorization, or through the idea of “gender” to which women have innate differences to men that would, for example, make them less productive or would make it necessary to control their bodies for the reproduction of the labor force or the inheritance system. In this sense, it is not possible to think of an explanatory model as race + class + gender, but rather a meeting of the three structures whose functioning is interconnected.

Considering the socioeconomic issue of the precariousness of life in peripheral and semi-peripheral countries of capitalism, it is somewhat obvious that diseases and epidemics have greater and more serious proportions in these places, and that they are mostly related to treatable diseases. The challenge, then, is to shift this exclusivist perspective on income and social class - or “vulnerability factors” - to insert the debate on gender, race and racism into the illness, death from AIDS and unemployment of PLWHA.

Stigma of AIDS

According to Goffman (1981), in Ancient Greece, “stigma” was an idea associated with body marks used to identify people as slaves or other inferior categories. This social “brand” characterizes the person by an undesirable difference, which was related mainly to physical or health aspects of the individual (for example, Goffman cites people with disabilities or psychic suffering), or even to moral behaviors considered “deviant”

(such as homosexuality). Stigma, therefore, would be the root, the mark of discrimination and the categorization of various differences.

According to Parker and Aggleton (2001), stigma is contextual, strategically employed, historical, and it produces and reproduces social inequities. With regard to HIV/AIDS, it develops into stigmatization and discrimination, triggering negative social reactions that do not occur exclusively, given that the risk of contagion by STI already aroused the sense of “divine punishment” for sexual sin, or even the isolation of infected people for fear of spreading the disease.

Some powerful ideas about AIDS have been mobilized by society to legitimize stigmatization. Parker and Aggleton (2001, p.19) divide them into: AIDS seen as death; AIDS as (moral) punishment; AIDS as horror; AIDS as war (fighting aids); AIDS as a crime (regarding the innocent and the guilty of transmission); AIDS as shame; and AIDS as “the other” (in which AIDS is seen as something that affects those who are different).

For Anselmo Alós (2019, P.2), an illustration of the stigma aspects of AIDS is the association with death and suffering, as happens in the picture of David Kirby, an activist living with HIV, taken by Therese Frary. In the picture, the AIDS patient agonizes in terminal phase surrounded by his family, who can do nothing but suffer with his imminent death, as in the famous Pietá. Analyzing the literary production of fiction about AIDS, the author finds that the main motto of these texts is death and love, and generally the latter is related to loss of affection. All of this corroborates an image of extreme pain and loss of complexity in the subjectivities of people living with HIV/AIDS (Alós, 2019, P.5).

Besides these legitimizing ideas of stigmatization, Parker and Aggleton (2001, p. 20) highlight that the stigma of AIDS does not work without other factors of inequality and exclusion previously existing in society and culture, which to a certain extent, is related to the previous discussion of “intersectionality”, although the authors do not use this term. According to Parker and Aggleton, four axes of stigma are very present in responses to the AIDS epidemic worldwide, namely: “(1) stigma in relation to sexuality;

(2) stigma in relation to gender; (3) stigma in relation to race or ethnicity; and (4) stigma in relation to poverty or economic marginalization” (Parker; Aggleton, 2001, p. 20).

In view of these developments of the stigma of AIDS, the paths narrated by young people who were born with HIV (precisely in a time before anti-HIV drugs) are permeated by their impacts, which combine with aspects of gender, race and class oppressions.

Activist experience and demands for access to work and welfare for PLWHA

I start this section by talking about the Course of Youth Participation and Human Rights and HIV / AIDS Activitism in São Paulo State, held by RJSP+ in collaboration with the São Paulo CRT DST/AIDS. It was in this course that two phenomena were born which I consider important, both for my life in particular and for HIV/AIDS activism with the Youths: the Loka de Efavirenz collective, of which I am currently a member with 13 others, which stood out in digital activism on the topic, and the signal for building the WG on Vertical transmission of HIV and Youths in the São Paulo CRT STD/AIDS, through RJSP+.

According to a memory of the second meeting, held on May 31, 2017, the WT of Vertical Transmission and Youths was born from a discussion table of the Youth Participation Course of 2016. Historic activists Nair Brito⁸ and Micaela Cyrino⁹, as well as sanitary doctor Paulo Roberto Teixeira, attended this discussion table. Thus, the creation of the WG by RJSP+ was arranged as an initiative of civil society which invited the State STD / AIDS Program, non-governmental organizations

(NGOs) working in São Paulo with young people born with HIV and society in general.

In this WG, in collaboration with activist and researcher Lili Nascimento¹⁰, we were in charge of both the coordination of the meetings and a chat circle in NGOs/AIDS, entitled “A straight talk on jellybeans, Efavirenz, teas and other anxieties”, held between June and November 2017 in two NGOs that serve young people living with HIV/AIDS. At the time, the formation of the group was reported by Agência de Notícias da AIDS in an article by Daiane Bonfim (2017).

At these meetings, held in collaboration with the São Paulo STD/AIDS CRT, we always relied on the participation of Analice Oliveira, a social worker with the STI/AIDS Program and a fellow fighter in the social movements who is very important for the SP+ Youth Network, and of some other health professionals requested by the young people who had a bond with them, whether from the CRT or other health services. The purpose was to make a survey of the needs of these young people, and in the conversations, the loss of the disability benefit, or OLSW, as they usually call it, as well as the difficulties with the side effects arising from the long-term use of antiretrovirals, were frequently mentioned. Insertion in the labor market is also very difficult for those who deal with the stigma of AIDS, education deficiencies and the need for chronic treatment.

In this sense, in the second chat circle, held at NGO I¹¹ with approximately 20 young people in July 2017, I remember the testimony of a young black man, whom I will call by the fictitious name of Júlio, who worked with music and confided how difficult it was to adhere to treatment due to the

8 Nair Brito is an activist of the AIDS social movement, a teacher, and one of the pioneers in receiving antiretroviral treatment in Brazil. She undertook a judicial struggle and intense militant mobilization in the 1990s.

9 Micaela Cyrino is a black activist born with HIV and a visual artist. She has a historical importance in the youth movement living with HIV/AIDS as one of the founders of the National Network of Adolescents and Young People Living with HIV / AIDS (RNAJVHA). She has renowned works, such as the performance “Cura”, in addition to having coordinated the 1st Regional Seminar on Vertical Transmission and HIV Infection in Adolescence.

10 Lili Nascimento is a black activist, visual artist and psychology student born with HIV. She was head of the SP+ Youth Network, secretary of the National Network of Adolescents and Young People living with HIV/AIDS and today she is a member of the Loka de Efavirenz collective. She also conducts research on childhood and medicalization of AIDS.

11 To ensure the confidentiality of the identities of the participants in the chat circles, I do not disclose the names of the institutions to avoid possible associations by readers who could know them and the people they assist, as the AIDS movement is made up of many people who are acquainted with one another. They will, therefore, be called NGO I and NGO II.

lack of opportunities “in the ‘hood” - that is, in the neighborhood where he lived, in the outskirts of South São Paulo - and being born with HIV was an aggravating factor. Júlio was approximately 20 years old and a self-declared heterosexual, and he lost his parents to the AIDS epidemic in the 1990s. He had spent many years in a shelter home for children and adolescents living with HIV. His concerns about financial survival - and therefore social class - as well as racism were poignant.

The study by Oliveira, Negra and Nogueira-Martins (2012), which interviewed 18 young people born with HIV users of an infectology outpatient clinic about their life projects, also pointed out the difficulty to adhere to treatment as preponderant and recorded strategies used by young people to get around the bad feeling of taking the medicine, or even confessions of periods in which they stopped continuous use of the medication.

An excerpt from Júlio’s testimony further details his concerns: “*With the OLSW, things were easier, you had enough not to go hungry. But a lot of people leave the shelter [for children and adolescents living with HIV] at 18, and nowadays they don’t have the OLSW anymore*” (Júlio). He goes into detail about his connection with the hip-hop culture and ends up also giving an ethnic testimony: “*I am black, and I am followed by the police if they suspect me for some reason... I struggle to hold down the jobs I get because if the boss pulls up my record, he will have second thoughts, and living off your art is not easy, especially for a black man*” (Júlio). His narrative was also one of loss, as he mentions his memory of black friends who died as a result of AIDS.

A white heterosexual young woman who I will call Larissa, a resident of Northwest São Paulo who at the time was going to meetings with her baby son using public transport, showed very clearly the difficulty to adhere to the medication. She reported being very tired from having to cope with a chronic infection since her childhood, losing her parents, having to see the lipodystrophy on her own face¹² and the struggle to come up with a long-term life plan. In addition, she suffered physical symptoms such as vomiting

and nausea when taking her medication, and even with follow-up of health workers, she was not able to adhere to this treatment. Subsequently, she had complications due to AIDS and died.

This young woman, who dreamed of having a child and had in her pregnancy the period in which she was most successful in adhering to antiretroviral treatment so that her child would be born without HIV, told me a shocking phrase: “*I only hold on to life for my son, but I worry a lot if my friends have food to eat, or if they will have work*” (Larissa). I remember asking if she herself did not want to go to college, work in some specific profession: “*I’m studying for a master’s degree in Social Science*”, I remember saying. She replied with a disturbingly calm voice: “*No, we were not raised for that*”. She had also lost the OLSW and lived on family help, since due to her poor health, she could not get a job. Larissa attended all the chat circles at the two NGOs.

NGO II allowed us to hold three meetings that also had emblematic testimonies about the conditions and aspirations of these young people. Unlike the other NGO, NGO II had not been a day care center, but it was created in the pediatric ward of a São Paulo hospital, and it eventually grew to acquire its own headquarters and autonomous administrative body to the hospital. The main activities promoted by NGO II were, besides theater, dance, visual arts, music and general assistance, lectures at schools to promote prevention and sex education, as well as visits to health services to receive other young people living with HIV. At this NGO, young people were also closely connected to raising awareness of adolescents at public schools and youth culture groups.

On a piece of brown paper drawn up at the first meeting, at which I recall there were approximately 15 young people in attendance, there are the testimonies “stigma” and “we were not raised for life”. I remember one of the most moving testimonies, given by a young black woman whom I will call Cláudia. She was a bisexual young woman living in a town in the São Paulo Metropolitan Area, in a poor peripheral neighborhood, but in “a good house with *three-rooms*” (Cláudia). She was around

¹² This is the atypical redistribution of body fat due to some anti-HIV medications, which can cause discomfort - including aesthetic discomfort - to ART users (Coura; Guerra; Neri, 2011).

19 years old at the time, her source of income was her work at NGO II and she was struggling greatly to get jobs at other companies. This concern about the position in social classes and employability merged with her fears of sexism, affective loneliness (dilemmas of the “gender” marker) and accounts of stigma of AIDS. In this aspect, these oppressions merged.

Cláudia had a history of difficulty adhering to medication and she had witnessed the death of friends in childhood and adolescence. She also reported daily struggles with side effects of old drugs and memories of discrimination:

When I was little, AIDS was death. And I was raised for death, they didn't believe I would live. So, life at school was harder, my performance at school was much worse, and I feel a hole in my education. My face has marks [from lipodystrophy] because of the meds, and this is all very difficult. And when it comes to looking for a job, it is very difficult, first because my education is lacking, sometimes I manage to find work, but when I have my first appointments with the infectologist, the boss doesn't want me anymore. And how that I don't have the OLSW anymore, what am I going to do? And also a lot of people left the shelters with nothing. (Cláudia)

Cláudia's statement illustrates what Oliveira, Negra and Nogueira-Martins (2012) present: young people carry on with their life projects under construction and reconstruction, however, they are from a generation that grew with the prospect of death due to the lack of effective treatments in the 1980s and 1990s.

I also highlight the testimony of a young black man, whom I call Tales, who declared himself heterosexual. He brought the information that fatherhood and black music, specifically hip-hop, had “saved him”, but “having to make ends meet without the OLSW since the age of 18, and now with a healthy child, is for hustlers, especially when you are black. And there is also this thing [racial] prejudice, right,?” (Tales). Tales was in a stable relationship with a young HIV-free woman, and his son had been born shortly before.

For Tales, fatherhood was very important because, according to his account, his education and socialization took place at a shelter home for children and adolescents living with HIV. He reports experiencing the death of friends in childhood and adolescence. “*Being the father of a boy without HIV is wonderful for me, especially because I know that he will have a family*”, he says. Providing for himself and his family is a challenge for this young black man who was born and lives with HIV, and such concerns presented in his report show the interconnection and synergy of social markers of difference, or intersectionality.

Another participant was Natália, a young black lesbian who lived in a brick and mortar house. The neighborhood where she lives, in the outskirts of São Paulo, has a history of land occupations by social housing movements. At the time, she was close to turning 20 and reported a conflict with her doctor. The health worker who followed the AIDS epidemic from its beginning told her that having HIV, at that moment, was just “a matter of taking a little medicine”, and that she should be grateful that there were drugs instead of complaining about taking the daily pills:

Be grateful for what? Taking medication does not fill my stomach and it does not give me peace of mind. If I don't do a bunch of odd jobs to have food, I will end up like Santiago, who went to live precariously in an occupied building downtown and drank dirty water, and he couldn't take medicine because he was vomiting, I couldn't do it. Besides, it bothers me when I am watched in the shops, or when they tell me in a job interview that I am not the right fit for the company, just because I am black and lesbian. (Natália)*

Again, the concern with employability and income is mixed with housing, gender, sexuality and race, according to the scheme presented by Parker and Aggleton (2001) on how the stigma of AIDS blends with other forms of oppression already existing in societies.

Santiago*, mentioned by Natália, was a young heterosexual black man who had lost his parents in the 1990s and had been raised by relatives, but around the time when the records

were collected, he was keeping away from them. He was friends with Natalia and the others who had joined the chat circle. An activist and assisted by NGO II, he died of complications due to AIDS after living for some time in very precarious housing conditions in the occupation of an abandoned building in center of the town where he lived. According to reports, he may have ingested contaminated water. The story of this boy was very moving for all who were in attendance.

These “Straight Talk” meetings and the meetings of the WG of Vertical Transmission and Youths led to the construction for the First Regional Seminar on Vertical transmission and HIV Infection in Adolescence, held in 2018. Its political statement includes among its major demands the reinstatement of the disability benefit for young people born with HIV, in poverty and vulnerability, as well as laws to stimulate employability and access to education - besides more specific demands for improvement in Health Services (ICA letter, 2018).

I would like to highlight, as a transvestite, the absence of transgender people among the participants in these round-table discussions, which is more common in my experience with young people living with HIV, but who became infected through sexual intercourse. This is something to be investigated in future studies. Another population who I also did not have the chance to see in these NGOs were people living in the streets or in very precarious urban occupations, with the sole exception of the story of Santiago.

What about the pensions?

With regard to the drama of un-retirement in the screening conducted by the National Institute of Social Security (INSS), my first contact with the narrative was in late 2017 through Analice Oliveira, a social worker at the CRT and a close partner in the actions of RJSP+. She reported to me cases of people with severe chronic illness, retired by the INSS due to invalidity, who were losing their benefits. Shortly after, an activist contacted me through social networks. Paulo (a fictitious name), a poet and musician in his 60s, wanted to report the drama of his companion, who had lived for many years with

HIV and had lost his invalidity pension. He reached out to me because of my activism in the Loka de Efavirenz collective. His purpose for doing so was his intention to carry out a campaign with a petition on the “Public Petition” portal and and social media postings to raise to awareness of activists about the drama of people who were out of the labor market for many years and used medication from a time before ART, which caused much more harmful and permanent side effects. Paulo's spouse, for example, had significant bone problems and lipodystrophy, conditions that were ignored in the INSS expertise examination, according to what was reported to me.

I spoke with members of the Loka de Efavirenz collective Loka to explore how the media has addressed the AIDS epidemic and its developments over the years, and how press has addressed the withdrawal of the benefits. The Loka de Efavirenz collective, besides using digital activism to condemn the withdrawal of pensions, also decided to include employment and welfare among its demands (focusing on the reality of the youth) - through the engagement of some of its members, in conjunction with RJSP+ - for spaces of activism of young people living with HIV. The main one was, notably, the I Regional Seminar on Vertical Transmission and HIV Infection in Adolescence, held in September 2018.

In September 2019, another important space for the youth was the dispute over the idea that employment and welfare are crucial for the lives of PLWHA. At the first State Meeting of Youth and HIV/AIDS of the São Paulo CRT DST/AIDS, these guidelines were again the focus of the political statement of the 50 young people living with HIV/AIDS. Among the demands, items 4 and 26 called for the approval of Bill No. 8400/2017, introduced by Congressman Pompeo de Mattos (PDT-RS), which would decrease welfare taxes for companies hiring PLWHA. In mid 2019, the cases gain prominence in the media. One of the main articles denouncing the withdrawal of pensions was published on the online portal of BBC Brazil. The headline asks: “Who will want an employee with HIV?”, says man who lost his pension after 13 years” (Alegretti, 2019). The report described the dramatic situation experienced by PLWHA who were under risk of losing their source of income due to the INSS screening of beneficiaries, which endangered the

welfare benefits of 59,5 thousand people living with HIV/AIDS and resulted in the termination of pensions and sickness benefits in many cases.

Another news report, published by news portal Projeto Colabora, says that a single NGO, Grupo Pela Vida, received a demand for around 60 cases of people who lost their pensions (Vieira, 2009). In general, they are individuals who have had permanent consequences from another time of the AIDS epidemic, with more acute opportunistic infections, such as lipodystrophy, chronic kidney problems, in addition to the impact of social stigma itself.

To support people who were un-retired and prevent people who still had their benefits losing them, other important organizations of the AIDS social movement¹³ articulated with different actors from the State and civil society to revert the loss of these pensions. These organizations put together a defense effort with different political parties and mandates, as well as criticism campaigns on social media.

I highlight the intense advocacy action of the activist Renato da Mata, from the National Health and Human Rights Articulation (ANSDH), for the approval of Law No. 13.847/2019 (BRASIL, 2019a), which exempts from expertise examination the people retired due to HIV/AIDS, also called the “Renato da Matta Law”, sanctioned by the National Congress after President Jair Bolsonaro's veto. After intense mobilization to see it approved, the law managed to prevent the more than 59 thousand retired PLWHA from losing their benefits. However, it has not been able to resolve the “legal limbo” of people who had had their benefits suspended by the screening until then: the law is not retroactive, therefore, each individual who suffered losses had to file an individual lawsuit with lawyers and prosecutors. Social movements played a central role, providing legal advice and mediating the work with public defenders to undo the INSS inspection decisions. Thus, the problem of un-retirement still remains.

Final considerations

In both the case of the elderly who lost their pensions and the young people born with HIV/AIDS who lost their disability benefit without the support of any policies to help them enter the labor market, we can see one thing in common: the dismantling of labor and welfare rights prosecuted by neoliberal capitalism and the intensification of policies to reduce social spending and State action, which has a negative impact on adherence to treatment and the integral health of these people due to lack of income.

It is even more worrying, in a reality plagued by the health crisis of the covid-19 pandemic, to think about what will be and whether there will be public policy for these groups, which are more vulnerable than the general population. One of the policies of the current government, as is known, is to cut down on public and state spending. How are we going to maintain the structure of prevention and treatment of AIDS and other STIs and viral hepatitis during and after the health crisis? We can only effectively respond to AIDS if we start from the revolutionary notion of transformation and broad and indivisible freedom, of Angela Davis and Patricia Hill Collins, and with a logic of expanding social and labor rights, instead of dismantling rights and reducing the welfare State.

Reference

ALEGRETTI, L. ‘Quem vai querer um funcionário com HIV?’, diz homem que perdeu aposentadoria após 13 anos. *BBC News Brasil*, Londres, 29 jul. 2019. Disponível em: <https://www.bbc.com/portuguese/brasil-49132695>. Acesso em: 1 jun. 2021

ÓS, A. P. Corpo infectado/corpus infectado: Aids, narrativa e metáforas oportunistas. *Revista Estudos Feministas*, Florianópolis, v. 27, n. 3, p. 111, 2019. DOI: 10.1590/1806-9584-2019v27n357771

13 They are the following: the São Paulo State NGO /AIDS Forum (FOAESP), the National Network of People Living with HIV/Aids (RNP+), the Brazilian interdisciplinary Association of AIDS (ABIA), the National AIDS Articulation (ANAIDS) and the National Health and Human Rights Articulation (ANSDH).

BONFIM, D. Rede de Jovens SP+ e CRT-SP iniciam GT sobre transmissão vertical do HIV e juventudes. *Agência de Notícias da Aids*, São Paulo, 19 abr. 2017. Disponível em: <https://agenciaaids.com.br/noticia/rede-de-jovens-sp-e-crt-sp-iniciam-gt-sobre-transmissao-vertical-do-hiv-e-juventudes/>.

Acesso em: 25 mai. 2021.

BRASIL. Lei n. 13.847, de 24 de julho de 2019. Altera a Lei nº 8.213, de 24 de julho de 1991, para dispensar de reavaliação pericial a pessoa com HIV/Aids aposentada por invalidez. *Diário Oficial da União*, Brasília, DF, 21 jun. 2019a, Seção 1, p. 2. Disponível em: http://www.planalto.gov.br/ccivil_03/_Ato2019-2022/2019/Lei/L13847.htm. Acesso em: 10 out. 2019.

Brasil. Ministério da Cidadania. Benefício de Prestação Continuada (BPC). *Governo Federal*, Brasília, DF, 25 nov. 2019b. Disponível em: <https://www.gov.br/cidadania/pt-br/acoes-e-programas/assistencia-social/beneficios-assistenciais-1/beneficio-assistencial-ao-idoso-e-a-pessoa-com-deficiencia-bpc>. Acesso em: 13 out. 2020.

BRASIL. Ministério da Saúde. Departamento de Doenças de Condições Crônicas e Infecções Sexualmente Transmissíveis. TELELAB. *Inserção de pessoas vivendo com HIV é tema de reunião interministerial*. Brasília, DF, 21 fev. 2016. Disponível em: <https://telelab.aids.gov.br/index.php/2013-11-14-17-44-09/item/373-insercao-de-pessoas-vivendo-com-hiv-aids-no-mercado-de-trabalho-e-tema-de-reuniao-interministerial>. Acesso em: 1 ago. 2021.

BRASIL. Ministério da Saúde. Secretaria de Vigilância em Saúde. *Boletim epidemiológico. HIV/Aids 2020*. Brasília, DF, n. esp., dez. 2020. Disponível em: <http://www.aids.gov.br/pt-br/pub/2020/boletim-epidemiologico-hiv-aids-2020>. Acesso em: 25 abr. 2021.

Carta Política do I Seminário Regional de Transmissão Vertical e Infecção do HIV na Adolescência - sudeste. São Paulo, 23 set. 2018. Disponível em: <http://abiaids.org.br/wp-content/>

[uploads/2018/10/2018-carta-do-seminario-jovens-e-hiv.pdf](https://www.marxists.org/brasil/2018/10/2018-carta-do-seminario-jovens-e-hiv.pdf). Acesso em: 10 jun. 2021.

COLLINS, P. H. Se perdeu na tradução? Feminismo negro, interseccionalidade e política emancipatória. *Revista Parágrafo*, São Paulo, v. 5, n. 1, p. 617, 2017.

COURA, C. F.; GUERRA, V. R.; NERI, L. C. L. Lipodistrofia em crianças infectadas com HIV sob terapia anti-retroviral: o desafio do século XXI. *Pediatria*, São Paulo, v. 33, n. 1, p. 4551, 2011.

DAVIS, A. *Mulheres, cultura e política*. Tradução de Heci Regina Candiani. São Paulo: Boitempo, 2017.

DAVIS, A. *Women, Culture & Politics*. Nova York: Vintage Books, 2011.

DIREITOS da pessoa com HIV: Entenda a aposentadoria por invalidez e o que fazer caso tenha perdido o benefício. *Agência de Notícias da Aids*, São Paulo, 14 mar. 2019. Disponível em: <https://agenciaaids.com.br/noticia/direitos-da-pessoa-com-hiv-entenda-a-aposentadoria-por-invalidez-e-o-que-fazer-caso-tenha-perdido-o-beneficio/>. Acesso em: 30 mar. 2020.

ELLIS, C.; ADAMS, T. E.; BOCHNER, A. P. Autoethnography: an overview. *Historical Social Research*, Colônia, v. 36, n. 4, p. 273290, 2011. DOI: 10.12759/hsr.36.2011.4.273-290

FERREIRA, R. C. M; FIGUEIREDO, M. A. C. Reinserção no mercado de trabalho. Barreiras e silêncio no enfrentamento da exclusão por pessoas com HIV/AIDS. *Revista Medicina*, Ribeirão Preto, v. 39, n. 4, p. 591600, 2006. DOI: 10.11606/issn.2176-7262.v39i4p591-600

GEERTZ, C. *A interpretação das culturas*. Rio de Janeiro: LTC, 2008.

GOFFMAN, E. *Estigma*: notas sobre a manipulação da identidade deteriorada. Tradução de Mathias Lambert. 4. ed. São Paulo: LTC, 1981.

GONZALEZ, L. A juventude negra brasileira e a questão do desemprego. In: Conferência Anual do African Heritage Studies Association, 2., 1979, Pittsburgh. *Resumos [...]*. East Point: AHSA, 1979. Disponível em: <https://www.marxists.org>

org/portugues/gonzalez/1979/04/28.pdf.
Acesso em: 22 maio 2021.

HIRATA, H. Gênero, classe e raça: interseccionalidade e consubstancialidade das relações sociais. *Tempo social*, São Paulo, v. 26, n. 1, p. 6173, 2014.

DOI: 10.1590/S0103-20702014000100005

MAGALHÃES, C. E. A. de. Autoetnografia em contexto pedagógico: entrevista e reunião como locus de investigação. *Veredas Temática*, Juiz de Fora, v. 22, n. 1, 2018.

OLIVEIRA, L. L.; NEGRA, M. D.; NOGUEIRA-MARTINS, M. C. F. Projetos de vida de adultos jovens portadores de HIV por transmissão vertical: estudo exploratório com usuários de um ambulatório de infectologia. *Saúde e Sociedade*, São Paulo, v. 21, n. 4, p. 928939, 2012.

DOI: 10.1590/S0104-12902012000400012

PARKER, R.; AGGLETON, P. *Estigma, discriminação e Aids*. Rio de Janeiro: Associação Brasileira Interdisciplinar de AIDS, 2001. (Coleção ABIA, Cidadania e Direitos, n. 1).

PERRUSI, A.; FRANCH, M. Carne com carne: gestão do risco e HIV/Aids em casais sorodiscordantes no Estado da Paraíba. *Política & trabalho*, João Pessoa, n. 37, p. 179200, 2012.

REDE de Jovens São Paulo Positivo. *Ata da 2ª reunião do Grupo de Trabalho sobre Transmissão Vertical e Juventudes*. São Paulo, 31 maio 2017.

Disponível em: <https://www.facebook.com/notes/3720943314635566/>.

Acesso em: 22 mai. 2021.

REDE DE JOVENS SÃO PAULO POSITIVO.

Carta política dos jovens no I Encontro Estadual Juventudes e HIV/Aids do CRT DST/Aids de São Paulo. *Fórum das ONG/Aids do estado de São Paulo*, São Paulo, 12 set. 2019. Disponível em: <http://www.forumaidssp.org.br/noticia.php?id=114&carta-politica-dos-jovens-no-i-encontro-estadual-juventudes-e-hiv-aids-do-crt-dstaids-de-sao-paulo>. Acesso em: 1 jun. 2021.

STOLCKE, V. Sexo está para gênero assim como raça para etnicidade?. *Estudos Afro-Asiáticos*, Rio de Janeiro, n. 20, p. 101119, 1991.

TANCREDI, M. V. *Sobrevida de pacientes com HIV e AIDS nas eras pré e pós terapia antirretroviral de alta potência*. 2010. 140 f. Tese (Doutorado em Saúde Pública) - Faculdade de Saúde Pública, Universidade de São Paulo, São Paulo, 2010.

TESTA, E. C. et al. Análise das reações adversas ao Efavirenz em pacientes do Instituto de Pesquisa Clínica Evandro Chagas/FIOCRUZ. *Revista Brasileira de Farmácia*, Rio de Janeiro, v. 90, n. 1, p. 8185, 2009.

VERSIANI, D. B. Autoetnografia: uma alternativa conceitual. *Letras de Hoje*, [s.l.], v. 37, n. 4, 2002.

VIEIRA, M. Portadores de HIV perdem aposentadoria após pente-fino do INSS. *Projeto Colabora*, Rio de Janeiro, 15 jan. 2009. Disponível em: <https://projetcolabora.com.br/ods3/portadores-de-hiv-perdem-aposentadoria-apos-pente-fino-do-inss/>. Acesso em: 20 mar. 2020.

WILLIAMS, R. Base e superestrutura na teoria da cultura marxista. In: WILLIAMS, R. *Cultura e Materialismo*. Tradução de André Glaser. São Paulo: Editora Unesp, 2011.

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