



The daily life of people living with HIV in Bissau, Guinea-Bissau: perspectives, challenges and vulnerabilities

Cotidiano de pessoas que vivem com VIH em Bissau, Guiné-Bissau: perspectivas, desafios e vulnerabilidades

Vida diaria de las personas que viven con VIH en Bissau, Guinea-Bissau: perspectivas, desafíos y vulnerabilidades

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ABSTRACT

Objective: to understand perspectives and challenges in the daily lives of people after the discovery of living with HIV in Bissau, Guinea-Bissau, considering different contexts of vulnerability. **Method:** an exploratory-descriptive study conducted through semi-structured interviews with sixteen people living with HIV attending a hospital in the city of Bissau. We used the thematic content analysis technique. Participants' reports were analyzed following two empirical categories: *Discovery, impacts and challenges of living with HIV*; and *Experience with antiretroviral therapy: new beginning and perspectives*. **Results:** the results indicate that the challenges start with the disclosure of diagnosis, which arouses a diversity of feelings and behaviors. Stigma and discrimination encourage the adoption of confidentiality about serological status, which increases the fragility of emotional support in coping with seropositivity. Antiretroviral therapy was seen as a hope for coping with the disease. Social vulnerability was the dimension that stood out the most, and human rights violations involving people living with HIV were verified. **Conclusion and implications for practice:** the study makes it possible to understand the perspectives, challenges and vulnerabilities of people living with HIV. Living with HIV deserves special attention from health professionals who work in the care of these people, highlighting as a contribution the relevance of comprehensive health care, in which ethics and subjectivity are present.

Keywords: Anti-Retroviral Agents; Guinea Bissau; Health Vulnerability; HIV Seropositivity; Public Health.

RESUMO

Objetivo: compreender as perspectivas e desafios no cotidiano de pessoas após a descoberta do viver com VIH em Bissau, Guiné-Bissau, tendo em vista diferentes contextos de vulnerabilidade. **Método:** estudo exploratório-descritivo, que utilizou entrevista semiestruturada com 16 pessoas vivendo com VIH, acompanhadas em um hospital de Bissau. Empregou-se técnica de análise de conteúdo temática. Os relatos dos participantes foram analisados a partir de duas categorias empíricas: *A descoberta, os impactos e os desafios de viver com VIH*; e *Experiência com o antirretroviral: recomeço e perspectivas*. **Resultados:** sinalizaram que os desafios iniciam com a revelação do diagnóstico que, geralmente, desperta uma diversidade de sentimentos e comportamentos. O estigma e a discriminação estimulam a adoção do sigilo sobre o *status* sorológico, resultando na fragilidade de suporte emocional no enfrentamento à soropositividade. A terapia antirretroviral foi vislumbrada como esperança para o enfrentamento da doença. A vulnerabilidade social foi a dimensão que mais se destacou, e violações dos direitos humanos foram constatadas. **Conclusão e implicações para a prática:** o estudo permite compreender as perspectivas, desafios e vulnerabilidades de pessoas que vivem com VIH. O viver com VIH merece atenção especial por parte dos profissionais de saúde que atuam no cuidado dessas pessoas, destacando-se como contribuição a relevância de um cuidado de saúde integral, em que a ética e a subjetividade estejam presentes.

Palavras-chave: Antirretrovirais; Guiné-Bissau; Saúde Pública; Soropositividade para HIV; Vulnerabilidade em Saúde.

RESUMEN

Objetivo: este estudio cualitativo tuvo como objetivo comprender perspectivas y desafíos en la vida cotidiana de las personas que viven con VIH en Bissau, Guinea-Bissau, considerando diferentes contextos de vulnerabilidad. **Método:** estudio exploratorio-descriptivo, que utilizó una entrevista semiestructurada con 16 personas que viven con el VIH, seguido en un hospital de Bissau. Se utilizó la técnica de análisis de contenido temático. Los informes de los participantes se analizaron a partir de dos categorías empíricas: *El descubrimiento, los impactos y los desafíos de vivir con el VIH*; y *La experiencia antirretroviral: un nuevo comienzo y perspectivas*. **Resultados:** los resultados indicaron que los desafíos comienzan con la divulgación del diagnóstico, que generalmente suscita una diversidad de sentimientos y conductas. El estigma y la discriminación fomentan la adopción del secreto sobre el estado serológico, lo que resulta en un apoyo emocional débil para hacer frente a la seropositividad. La terapia antirretroviral es una esperanza para hacer frente a la enfermedad. La vulnerabilidad social fue la dimensión que más se destacó y se encontraron violaciones a sus derechos humanos. **Conclusión e implicaciones para la práctica:** el estudio permite comprender las perspectivas, los desafíos y las vulnerabilidades de las personas que viven con el VIH. Vivir con VIH merece especial atención por parte de los profesionales de la salud que actúan en el cuidado de estas personas, destacando como aporte la relevancia de la atención integral en salud, en la que la ética y la subjetividad están presentes.

Palabras clave: Antirretrovirales; Guinea Bissau; Salud Pública; Seropositividad para VIH; Vulnerabilidad en Salud.

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INTRODUCTION

Over four decades, the Human Immunodeficiency Virus (HIV) epidemic has spread around the world, reaching the most diverse societies, becoming one of the greatest challenges of global public health. According to the Joint United Nations Program on HIV Global Statistics Summary, in the year 2020, there were 37.7 million people living with HIV (PLHIV); of these, 27.5 million (73%) had access to antiretroviral therapy (ART), and 1.5 million (3.9%) were new HIV cases. Deaths related to acquired immunodeficiency syndrome (AIDS) reached 680,000 (1.8%).¹

In the world, Sub-Saharan Africa (a group of African countries located in southern Sahara Desert) is the region most affected by the HIV epidemic. In 2018, approximately five thousand cases were recorded daily in adults and children, with more than 60% occurring in Sub-Saharan Africa.²

In Guinea-Bissau, a country located in sub-Saharan Africa, HIV is among the three most prevalent diseases, and the country is one of the few in the world with both virus subtypes (HIV type 1 and 2). In 2020, a prevalence of 3.0% (3.8% in women and 2.2% in men) was estimated in the population aged 15 to 49 years.³ In the same year, 1,700 cases of HIV were recorded in Guinea-Bissau, reaching an incidence of 1.23 per 1,000 inhabitants. The data also showed that approximately 60% of PLHIV had access to art and that the absolute value of AIDS-related deaths was 1,500.⁴ Through these data, it is clear that the number of deaths from AIDS-related causes is close to the number of cases recorded in 2020, which indicates the persistence of the HIV epidemic in that country, having as main factors the constant political and economic instability, the discontinuity of HIV policies and the growing susceptibility of vulnerable populations.⁵

In addition to the biological consequences, HIV carries a sign that frightens people in different societies. People's thinking and acting are influenced by the structures in which they are immersed and by values and norms shared in their environment, thus directing the relationships between environment-health-society. The World Health Organization and UNAIDS point out that, for an effective response to HIV, it is essential that there is a greater effort to contain stigma, which is configured as a driving factor of the HIV pandemic, so much so that its eradication is among the three pillars of the UNAIDS plan to achieve the goal of zero new HIV infections by 2030. However, understanding the different ways in which stigma enhances the risks of HIV at an individual level is still a challenge for its mitigation in institutional contexts.³

Considering the high prevalence of HIV, the low HDI (0.480, ranking 175th of the 189 countries),⁶ the marked cultural, ethnic, linguistic and religious diversity of Guinea-Bissau⁷ and the experience of living with HIV, which is largely subjective, suffering interference from cultural, religious, ethnic and economic aspects, it is important to know how people live such experience in a given context, taking into account their specificities. However, to the best of our knowledge (searches carried out in databases such as PubMed, EMBASE and Google Scholar, with no year and language limit), with the exception of a study that addressed health literacy with PLHIV in Bissau⁸ and a study on barriers and

facilitators to ART and compliance among HIV patients in Bissau, Guinea-Bissau,⁹ there are no scientific articles that analyze the ways people experience HIV infection and its treatment in Guinea-Bissau. Thus, this study aimed to understand perspectives and challenges in the daily lives of people after the discovery of living with HIV in Bissau, Guinea-Bissau, in view of different contexts of vulnerability in health.

METHOD

We adopted a qualitative, exploratory and descriptive approach, which makes it possible to understand the internal logic of groups, institutions and actors in relation to cultural values and representations of their history and specific themes, the relationships between people, institutions and social movements, and the historical, social and implementation processes of public and social policies.¹⁰ The study took place in the city of Bissau, capital of Guinea-Bissau, at the Outpatient Treatment Center (OTC) of *Hospital Nacional Simão Mendes* (HNSM), a reference for PLHIV. The service is public, and the services offered are tests for HIV detection, laboratory tests, follow-up and control consultations and dispensing of antiretroviral drugs.

The study had 16 participants, selected intentionally, through personal invitation in face-to-face approach. The inclusion criteria adopted were being Guinean, residing in Bissau, mastering the Portuguese or Creole language and being 18 years of age or older. Approximately 15 people refused to participate in the research or withdrew, with lack of time and recording the interview being the main reasons. Prior to the interviews, there was an insertion in the field to monitor the dynamics of the service in general.

The information was collected by a native researcher, a nurse, in one of the OTC rooms, through a semi-structured interview, with an average duration of 50 minutes, which was recorded and later transcribed in full. The script included sociodemographic aspects, conceptions about HIV, changes in daily life after HIV diagnosis, search for health care (formal and informal) and social support networks. The interviews were carried out from January to April 2019, and the inclusion of new participants was ended when the information collected proved to be repetitive (saturated), noting that the primary information was sufficient to achieve the objectives outlined and understand the object under study.¹⁰ Thematic content analysis was the technique chosen to analyze the information, unfolding in three phases: pre-analysis; material exploration; and treatment of results obtained/interpretation.¹⁰ Vulnerability and human rights was the theoretical framework used.¹¹

Vulnerability is a set of individual and collective aspects related to the greater susceptibility of individuals and communities to illness or injury and, inseparably, less availability of resources to protect against events that threaten their health.¹¹ The analyzes in the light of this theoretical perspective cover three dimensions – individual, social and programmatic – that are related to constitute the specificity of a health situation. In the individual dimension, it becomes possible to (re)know the events that are harmful to people's health, their trajectories, material and psychosocial differences; in the social dimension, social, cultural and human

rights protection contexts are analyzed; and in the programmatic dimension, policies and services from different sectors are analyzed as intermediary elements in the vulnerability process. Consequently, it is known that people and social groups that do not have their rights respected and guaranteed have worse profiles of health, suffering, illness and death.¹¹

The research was approved by the Research Ethics Committee of the *Universidade Federal do Rio Grande do Sul*, CAAE (*Certificado de Apresentação para Apreciação Ética - Certificate of Presentation for Ethical Consideration*) 3.060.595, and had the consent of HNSM's general direction, through the Institutional Acceptance Term. In order to preserve participants' identity, fictitious names were used in the description of results. The development of this study followed the Consolidated Criteria for Reporting Qualitative Research (COREQ).

RESULTS

Of the 16 participants in this study, 12 were female, and ages ranged from 21 to 59 years. All participants were literate, having three to 12 years of education. Seven participants declared themselves single; four said they were married; three said they were widowed; and two said they were divorced. Eight participants claimed to be unemployed; two claimed to be saleswomen; two worked in general services/cleaning; one was a mason in civil construction; and there was also a tailor, a fairer and a student. The time of use of ART among participants ranged from one month to 17 years. Participants' reports were analyzed from two empirical categories: *The discovery, impacts and challenges of living with HIV*; and *Experiences with antiretroviral therapy: new beginning and perspectives*.

The discovery, impacts and challenges of living with HIV

Upon discovering their serological status, some participants were indifferent to the positive test result. Knowledge about seropositivity did not trigger any different feelings or behavior, especially in the case where the person frequently tested for HIV:

I didn't feel uncomfortable [when I received the diagnosis]. [...] I was normal [...] as if nothing had happened. [...] because I was ready for that. In the last years of high school, when I went with my friends to take the test, some received positive results and cried a lot, and I was the person who comforted them. I lived with people with this disease. I always said that, even though I have this disease, I will only die on the day that God says it's the end of me (Simone, 34 years old, 1 year and 10 months of ART).

I was indifferent. [...] it was like nothing happened. I left everything in God's hands [...] I thought that the disease caused by the lack of this ceremony [certain traditional ceremony of the Balanta ethnic group] is what Europeans call HIV/AIDS. but when I came to do the HIV test, they

explained to me that it's not the same thing [...] (Rebeca, 21 years old, 1 year and 1 month of ART).

In both reports, the presence of religiosity was highlighted as a factor that justifies indifference to the discovery of seropositivity. The second report also notes the influence of sociocultural factors on indifference to receiving positive HIV diagnosis. However, in a different way, most participants revealed that the discovery of their diagnosis triggered a variety of feelings, such as surprise, sadness, anguish and fear, both in them and in the family members who came to know their serological status. Such feelings may result in behaviors such as crying or temporary social isolation, as illustrated in the following reports:

[...] in the first days. [...] I felt very bad, I walked away from social life and I had a lot of anguish, but then it went away (Marta, 29 years old, 1 month of ART).

[...] my oldest son knows and he was sad and afraid of losing me, like he lost his father (Eva, 47 years old, 12 years of ART).

When I told my sister, she got sad, she felt sorry for me [...] she started crying, and I also started crying [...] (Sonia, 33 years old, 4 years of ART).

I was not well. I even went to the center of Santa Luzia to do the test again to make sure it was really this disease, but I was told they were short of materials [...] I kept trying to digest the news and recover psychologically (Pedro, 32 years old, 1 year and 3 months of ART).

Today, I can tell you that it is still a burden, but that it has been decreasing over time (José, 28 years old, 4 months of ART).

I was worried for one, two, three months, a year and, as I was taking the medication and feeling well, then I started to consider it a normal disease (Mario, 59 years old, 11 years and 3 months of ART).

It was observed that the feelings reported were more exacerbated in the first moments after the discovery of HIV diagnosis and that, over time, they gradually diminished, becoming less and less present in the lives of these people and their families. Participants also reported the importance of family support and conversation with professionals:

[...] I talked to the psychologist, and she made me understand many things about the disease [...] my sister and my boyfriend, they always talk to me about it and always give me strength (Sonia, 33 years old, 4 years of ART).

Only my mother and my boyfriend [know the diagnosis] [...] my boyfriend supports me very psychologically. He always cheers me up and tells me that it is a normal disease. Since I'm on medication, the disease won't be able to get me. He always advises me to continue treatment

according to medical recommendations (Leticia, 35 years old, 1 month of ART).

As for the impacts and main challenges faced when living with HIV, participants highlighted the fear of being recognized by society as PLHIV:

None of my family or friends know that I have this disease [...]. If I tell one person, out of the blue everyone will know, and they will start talking badly about me. They'll gossip and point the finger at me, saying that there goes a person who has AIDS, and that's not good. This is a disease that requires complete secrecy. Only God and health professionals who care for us should know (Rebeca, 21 years old, 1 year and 1 month of ART).

Anyone with this disease will have this fear [of people knowing about your diagnosis]. Society stigmatizes people with this disease and accuses them of leading a mundane life (Simone, 34 years old, 1 year and 10 months of ART).

The fear of other people knowing that I have this disease (Beatriz, 33 years old, 2 years of ART).

Nobody knows [about the HIV diagnosis], except my sister [...] I'm slowly talking to him [husband] and preparing him so I don't have to tell him all at once. [...] he is an uninformed, sexist and regressive man (Marta, 29 years old, 1 month of ART).

The reports of study participants pointed to a marked restriction in sharing information about seropositivity with family, friends and partners. Five reported not sharing their HIV status with anyone else, which, on the one hand, benefited the maintenance of the support received by providing a lower risk of discrimination but, on the other hand, it limited the possibility of providing psychological and emotional support for living with HIV.

Narratives such as Marta's also indicate that not disclosing a woman's HIV diagnosis to her partner (man) can also be associated with fear of possible aggressive behavior in the face of disclosure. It is believed that such behavior can range from verbal or physical violence to divorce, as HIV diagnosis in women is associated with promiscuity, as highlighted by Simone.

In addition to the above challenges, participants' reports also show that the diagnosis of HIV can instigate the discontinuity of carrying out work activities, as can be seen below:

[...] I think it was because of this illness that I lost my job [...] I worked at the hotel [name] when I was sick [...] [Dr. Fátima] also worked at the hotel [...] Dr. Fátima sent me to take a test here and then I showed her that it was positive and she advised me to follow the treatment [...]. After that, they decided to take me out of work (Pedro, 32 years old, 1 year and 3 months of ART).

[...] my cousin, who also works with me, came to me saying that I'm sick and I shouldn't be working with them

because everyone who was at that job was healthy people. I felt very bad and had to return home [...]. Only my mother [knows about the diagnosis] (José, 28 years old, 4 months of ART).

Both reports show difficulties in maintaining employment after diagnosis. In the first report, it is clear that job loss is related to discrimination motivated by prejudice against PLHIV. In the second report, stopping carrying out work activities may be associated with the weakness caused by HIV or by the side effects of ART.

Analyzing all participants' statements, the fragility of psychological and emotional support structure for those affected by HIV was observed, characterized by the absence or weak participation of family and/or friends in coping with seropositivity.

Another challenge highlighted by participants concerns the perceptions of physical and/or social limitations imposed by the disease. Despite the use of ART, some participants reported feeling debilitated or unhealthy from living with HIV, as shown in the reports:

I really like athletics, running, playing football, but now I can't run much because I feel a little weak (Mário, 59 years old, 11 years and 3 months of ART).

When I am among people, for instance, in a place of conviviality, despite not letting it show, I feel a little lonely and sad, because I feel that I am not like other people, I am not healthy like them (Paula, 38 years old, 1 year of ART).

[...] I can no longer do the same thing as my friends [...]. I know I have the disease and I have to avoid many things. Sometimes I do not feel comfortable with my colleagues because of this disease (Beatriz, 33 years old, 2 years of ART).

The main challenge is the thought itself, if I will be sane again someday in my life. [...] Usually when I'm alone [I think about it]. When I'm with other people, it doesn't happen. [...] (Leticia, 35 years old, 1 month of ART).

The perception of the limitations imposed by HIV seropositivity attracts negative feelings, such as sadness, which can result in new behaviors in the marital relationship and/or sexual life, as can be seen in the following report:

[...] when you know you have this disease, you end up setting limits on your sex life [...]. Infecting someone means you want to kill that person because you know that passing this disease to someone else is the same as killing them. [...] before having sex, you have to be well protected so that you do not infect the other person (Mário, 59 years old, 11 years and 3 months of ART).

I feel uncomfortable [for not having sex anymore], but I have to stay that way so I don't harm the other (Paula, 38 years old, 1 year of ART).

[...] I abandoned my [sex] love life [...] I don't want any man to have this disease because of me. [...] maybe it's the fear that I have of not having children and being like this [without building a family] (Cynthia, 33 years old, 8 years and 1 month of ART).

This choice can trigger feelings, such as loneliness and fear in relation to love life and family constitution or maintenance, especially in people who dreamed of marrying and having children, as mentioned by participant Cynthia.

Experiences with antiretroviral therapy: new beginning and perspectives

Participants reported understanding ART as a hope for coping with the disease, as it causes positive consequences, associated with better prospects for life, whether to prevent illness or for the person to be on an equal footing with anyone else with a chronic disease:

[...] it is a disease that degrades you physically and can lead you to death [...]. I feel like I should take medication so the disease doesn't get me. I know that if I stop, I will be very weak (Rebeca, 21 years old, 1 year and 1 month of ART).

The horrible thing is not having the disease, but refusing treatment, even though you have all the conditions to face the disease and live much longer. If you accept treatment, you will be like everyone else (Cynthia, 33 years old, 8 years and 1 month of ART).

It was observed that, regardless of the way of understanding the purpose of adopting the therapy, all participants reported improvement in the clinical picture after starting ART, highlighting the beneficial results of its use, as can be seen in the following statement:

[...] since I started taking the medications, I feel my body in great condition to this day (Sara, 43 years old, 3 years and 2 months of ART).

I returned to normal after starting treatment. Before I felt sick, I was very thin and I didn't even feel like eating (Pedro, 32 years old, 1 year and 3 months of ART).

Taking into account the importance and benefits of the proper use of ART, the participants were asked what the daily experience of following the therapy was like, according to the recommendation of health professionals, especially with regard to the use and timing of taking the antiretroviral (ARVs) agents. Of the 16 participants, 10 stated that they never stopped taking their ARVs at the indicated times:

I have never forgotten, because I watch a soap opera that starts at 10 pm and I always take it before watching

[...] I cannot allow the virus to multiply again with greater intensity [...]. No matter where I go, I always carry the medications in my bag (Simone, 34 years old, 1 year and 10 months of ART).

Six other participants reported having difficulties in taking the medications every day at the times recommended by health professionals. Forgetting to use it at the oriented times was highlighted as the main aggravating factor for compliance with the recommendations, as shown in the reports:

[...] sometimes, I fail to take at the right time. When I'm doing some work, I always forget [...] I leave to take at the next established time. [...] they told me to take it at 9:00 a.m. and 9:00 p.m., they didn't say if I could take it after the set time (Mário, 59 years old, 11 years and 3 months of ART).

[...] sometimes, I missed the time to take the medication and took it when I remembered. [I forgot] especially when I left home and ended up not taking with me (Eva, 47 years old, 12 years of ART).

The difference between the two participants in their understanding of the use of ARVs after the recommended time was noticed: while the first took it only on the following day, the second did it as soon as she realized she had forgotten it. However, for Rebeca, her poor ART compliance has another reason:

Sometimes I fall asleep before the time [9 p.m.] to take the medication [...] once, I went about a week without medication in this current pregnancy. [...] I felt a lot of physical discomfort when I took it, so I stopped taking it for a period (Rebeca, 21 years old, 1 year and 1 month of ART).

In addition to the side effects, another factor that can also interfere with the use of ART is its unavailability in the public network, as can be seen in the following reports:

[...] with a lack of medication, we spend a lot of time without taking the medication [...] currently, I am receiving the medication on a monthly basis, but it is not always common, sometimes there is a shortage [...]. I was worried and thinking that the drug factory stopped working (Mario, 59 years old, 11 years and 3 months of ART).

[...] I was so worried, because I'm pregnant and I didn't have the medication I was taking. If I do not take the medication, my son will have this disease (Sonia, 33 years old, 4 years of ART).

DISCUSSION

Religiosity and spirituality act as mechanisms for coping with stressors associated with HIV, favoring the acceptance of diagnosis,¹² insofar as they help people to develop an understanding of the world and of life itself, not only through their cosmology, but also through their daily practices, playing an important role in social support,¹³ as noted in Simone and Rebeca's reports.

However, the indifference of participants in the face of receiving the diagnosis cannot be dissociated from the ordinary character that HIV occupies in people's daily lives. In Simone's case, it is believed that her experience, conditioned by the social environment (some seropositive friends), possibly contributed to her trivializing the diagnosis, demonstrating how significant the situations of social vulnerability to which PLHIV are subjected are in the country. It is also understood that this outcome is a product of constant programmatic vulnerability to HIV, considering the inability of institutions to create and implement health policies and actions to control the epidemic in the country.

In Rebeca's case, it is believed that indifference to the diagnosis may also be related to disbelief in the existence of HIV or the belief that this virus is of mystical origin, reducing the impact of diagnosis. Research conducted by the Government of Guinea-Bissau has shown that sorcery is still associated with HIV infection. Nationwide, 19.7% of those surveyed stated that they contract HIV through witchcraft and/or supernatural ways, compared with 60.1% who said they did not believe in this means of transmission. Still, 20.2% do not know the answer,¹⁴ which unveils the individual and social spheres of vulnerability to HIV.

The discovery of HIV seropositivity generally raises uncertainties about the future and represents a point of metamorphosis in a person's life, which can change their way of being, relating and living in society, especially with friends and family, who are the closest people. It is noteworthy that this discovery is not configured as biographical rupture, but as continuity and element of confirmation that reinforces a biography and identity. The occurrence of illness is interpreted as a coherent event in situations of suffering, injustice, oppression, material deprivation and general adversities¹⁵ that characterize vulnerable contexts, resulting in situations of vulnerability in health care.

The discovery of HIV triggers negative feelings, such as injustice, fear, sadness, shame, terror, unbelief and surprise, and may encourage social isolation,¹⁶ as found in this study. In this situation, the search for other health services to confirm HIV seropositivity, as reported by Pedro, may be more related to the denial of the disease than to the lack of knowledge itself.¹³ It is, therefore, a strong context of vulnerability involving three components: individual (characterized by the feeling of being unprotected and fragile); social (by the way society deals with HIV, ie with prejudice and discrimination); and programmatic (resulting from non-attendance due to lack of materials at the health center).

Negative feelings should be considered as a worrying factor, as they can cause stressful situations that affect the social behavior of PLHIV as well as maintaining their physical and

mental health.¹⁶ These feelings, in addition to their social and emotional repercussions, are related to clinical and psychosomatic symptoms, and may even trigger depression of the immune system, leaving affected people more susceptible to HIV and opportunistic diseases.¹⁶

In addition to the time factor, highlighted as an element that influences the experience and resignification of living with HIV, favoring living with the diagnosis, family support is also essential for people. This happens mainly in the first moments after the diagnosis is confirmed, a period in which they need support for the acceptance of seropositivity, for the search for health care and for self-care and self-esteem promotion.

In the present study, most participants informed about their seropositivity to some of their relatives, such as their brother, mother and partner, who, in their understanding, would keep it a secret. Similar findings to this were also found in a study in South Africa, pointing out that most participants had informed their serological status to someone in the family, because, in their understanding, there was nothing more important than receiving family support. Most of the time, PLHIV chose their sister, mother or aunt as targets of communication and then waited for a longer period to inform others.¹⁷

The fear of being identified as a PLHIV has proved to be one of the main challenges in coping with living with HIV. The restriction or non-sharing of information about seropositivity with family and friends can be understood from two perspectives. On the one hand, as a way to neutralize the fear of families of having the infection and of losing social prestige in their communities, as they believe that maintaining secrecy will prevent the degradation of family ties, helping to maintain harmony and social support.¹⁸ On the other hand, as a social survival strategy, avoiding the risk of suffering discrimination arising from prejudice/stigma related to HIV, in the family or social environment, as reported by Simone. This reality was also observed in other studies,^{13,18} including one conducted in Tanzania, which pointed out the fear of discrimination as one of the main difficulties of living with HIV seropositivity.¹⁹

The results of a survey conducted in Burundi showed that the problem of stigma is widespread in Burundian society as all survey participants reported experiencing some kind of HIV-related stigma. Seven dimensions were identified: physical violence, verbal violence, discrimination, self-esteem, fear and insecurity, and health provider stigma.²⁰

The disclosure of their diagnosis to their male partner can be inhibited by the fear of violence, as reported by Marta. In a review survey²¹ with studies conducted in several sub-Saharan African countries (Uganda, Nigeria, Kenya, South Africa, Zambia, Ethiopia, Cameroon, Tanzania and Swaziland), it was found that 30% of HIV-positive women were victims of intimate partner violence. Partner violence, rejection, discrimination, abuse, financial abandonment and forced divorce were the main reasons for the non-disclosure of serological status. Women victims of intimate partner violence have greater difficulty in following health care for HIV positive status, and treatment interruption is common.²¹

Evidence like these reveals the situations of social vulnerability to which women living with HIV are exposed and the violation of their rights, with emphasis on the right to protection and security. Factors such as patriarchy, inequalities that affect women, sexism, female submission and gender violence present in the social context where the study was developed contribute to such vulnerability²²

The diagnosis of HIV can lead to unemployment or interfere with the performance of work activities. Confidentiality about the diagnosis is also used as a strategy to keep the job, since the disclosure of seropositivity can encourage discrimination and result in dismissal, as reported by Pedro and verified in qualitative research carried out with PLHIV in South Africa.¹⁸ This situation reveals the violation of PLHIV's human rights. Moreover, the performance of work activities can also be affected by physical limitations, as found in this study, whether caused by HIV or by ARV side effects, as in the case of adynamia, as also found in a study carried out in Ghan.²³ From this perspective, discrimination and physical limitation are understood as factors that trigger situations of social vulnerability of PLHIV.

The literature^{16,20,24} supports the findings of this research, in the sense that the perception of physical and/or social limitations imposed by the HIV diagnosis can trigger negative feelings, with the possibility of adopting certain behaviors, such as sexual abstinence. In a study conducted with 21 women living with HIV, prejudice, stigmatization and feelings such as sadness, guilt, fear and/or shame related to living with HIV were observed.¹⁶ Fear and guilt for perhaps being responsible for HIV transmission for triggering sexual abstinence were also observed.¹⁶

This situation is reflected as a product of individual vulnerability, since participants demonstrated that they did not understand that HIV protection devices (e.g., condoms) can be safe, that an undetectable viral load in the blood for more than six months prevents sexual transmission²⁵ or that HIV-positive women may have seronegative children. It is thus questioned whether participants had access to this information, as not making it available was a violation of their rights, specifically right to information.

In relation to ART, expressing the recognition of its benefit and perceiving improvement in the clinical picture after its beginning is a fundamental step for continuity of treatment. It is known that there is currently no medication with the ability to cure HIV infection; however, this therapeutic tool has the ability to suppress the replication of the virus and allows the immune system to regain the ability to fight the infectious agent.²⁶ To succeed, such a measure requires the conservation of high compliance rates,¹⁸ differently from what happens in participants' reality, who reported being aware of the importance of ART, but having difficulties in complying with it. Thus, the individual vulnerability dimension is revealed in the worsening of their health situation as a consequence of poor adherence to ART.

In a cohort study on health literacy with PLHIV in Bissau, the authors highlighted the participants' lack of knowledge about HIV and the use of ART.⁸ They observed a lack of knowledge as a barrier to treatment adherence and pointed to the need

to carry out health actions that provide information about HIV and encourage the appropriate use of ART throughout life.⁹ It is worth mentioning that the present study did not seek to assess participants' knowledge about the use of ART, but it was possible to notice differences in the understanding of its correct use, as in the case of Mário and Eva, which converges with the results found in the cohort study.⁸

The lack of knowledge about ART is an important factor for non-treatment or its mistaken use, endangering the safety of HIV-positive people with regard to possible damage to health.²⁷ In this context, nurses and other health professionals can adopt mechanisms, such as the implementation of health education groups in outpatient services, with the possibility that, through them, adequate knowledge is promoted for optimal ART compliance, in addition to strengthening the bonds between seropositive people and health services.²⁷

However, with a deeper look, it is clear that the social and programmatic component of vulnerability cannot be ignored in this analysis, because, in general, if poor compliance with treatment was restricted to lack of knowledge, health professionals would not have non-compliance issues, whether with medications, diets and/or physical activities. A study carried out in Mozambique shows that, in addition to the lack of an adequate understanding of the benefits of ART by PLHIV, factors related to local culture, gender issues, fear of revealing the diagnosis to third parties, the way in which health services are organized, social aspects such as hunger and financial and transportation difficulties, among others, also make it difficult to comply with ART.²⁸ Although these factors are not explicit in this study, they cannot be disassociated from participants' reality, considering the social context in which the study was developed.²²

The results of this study converge with those of a cross-sectional study conducted in Uganda,²⁹ where treatment compliance appeared as a challenge of living with HIV, ranging from not using medications at the right time and using the wrong doses to temporarily stopping medication use and not attending clinic appointments. The fear of disclosing HIV status to partnerships, drug-related factors and HIV stigma were the main barriers to initiation and initiation to ART.²⁹

A study conducted in Ghana found that the levels of support were 42.9% in the study population. Lower ART compliance was associated with low motivation, forgetfulness, frequent medication shortages, long waiting times, and worrisome side effects,²³ corroborating the statements of the participants of this study, especially Rebeca.

The analysis and understanding of how the factors associated with this (non-) compliance are perceived by HIV-positive people are essential for the improvement of health policies and practices aimed at improving the effectiveness of treatment. In this regard, a study developed with PLHIV⁹ in Bissau highlighted the need for further studies, focusing on research, development and assessment of interventions with regard to adherence to treatment and knowledge about HIV, since participants' lack of knowledge about the disease and the use of medication was observed.

Regarding the permanence of access to ARVs, there were reports about the interruption of use of ART due to the unavailability of these drugs in the public network, which is the only provider to the population. This lack of ARVs for HIV has been reported by the national and international press. A German broadcaster³⁰ reported that the lack of medication was caused by the Guinean government's limitation in transporting medications from Brazil to its territory, in a scenario of an increase of more than a thousand new cases in the first half of 2018.

The expansion of access to ART was a central goal for 2020 (90-90-90).³¹ Such a target was that 90% of PLHIV would know they have the virus; 90% of people diagnosed with HIV would receive antiretroviral treatment; and 90% of people on antiretroviral treatment would have viral suppression. This initiative aimed to contribute to the end of the AIDS epidemic in the world by 2030 within the scope of the Sustainable Development Goals.³¹ Therefore, it can be said that the lack of medication contributed to distance the country from its political commitment regarding the fulfillment of the 90-90-90 target and, consequently, the eradication of the AIDS epidemic at a global level.

A study on barriers to ART and compliance among HIV patients in Bissau points to obstacles to treatment costs and competing subsistence needs, poor infrastructure, perceived stigma and traditional practices. Study findings indicate that optimal ART compliance, especially in resource-limited settings, requires patients to gain adequate knowledge about HIV.⁹

The lack of ARVs puts at risk the physical well-being of PLHIV and, consequently, their lives. The perception of this risk and the possibility of future interruptions in the supply of these drugs aroused in participants feelings of constant fear and concern. Thus, it is understood that stopping the supply of ARVs to PLHIV also jeopardizes their overall well-being, characterizing the situation of programmatic vulnerability and exposing the violation of one of the most basic and fundamental human rights, the right to health.

CONCLUSIONS AND IMPLICATIONS FOR PRACTICE

It was found that the perspectives and challenges in PLHIV's daily lives begin with the disclosure of their diagnosis of seropositivity, which usually triggers a diversity of feelings, which can result in certain behaviors, such as social isolation, especially soon after the discovery, tending to decrease over time. On the other hand, the fear of discrimination arising from prejudice/stigma in relation to HIV remains constant and encourages the adoption of complete confidentiality or a marked restriction on sharing information about seropositivity, resulting in the fragility of psychological and emotional support structure in coping with their health condition.

Despite the importance of ART pointed out by participants, the difficulty in continuing its use was noticed, either due to socio-behavioral factors, or due to its unavailability in the public network. The analysis of situations of vulnerability showed the presence of three dimensions (individual, social and programmatic), with

emphasis on the social dimension, mainly related to prejudice and discrimination against PLHIV. The rights of these people are constantly violated, ranging from lack of access to information to lack of access to ART. Thus, understanding these factors and other nuances involved in living with HIV has become a growing need for health professionals. In this sense, it is essential to adopt a holistic approach to care for PLHIV, especially with regard to factors that affect the socio-emotional field and the use of ART for developing health care in an integral perspective, aiming at improving the quality of life of these people.

It is suggested the promotion of access, quality and diversity of psychological assistance offers and institutional support network aimed at this public, as well as the elaboration of a Unique Therapeutic Project (*Projeto Terapêutico Singular*), since the management of living with HIV is determined by the way people interpret the disease, living with HIV, its causes and time of living with the diagnosis. Living with HIV deserves special attention from health professionals who work in the care of these people, highlighting as a contribution the relevance of comprehensive health care, in which ethics and subjectivity are present.

The limitations of this study are related to the small number of men participating in comparison with the participation of women and the fact that the interviews carried out at the OTC may have inhibited the statements about possible barriers to care. Furthermore, unique encounters with participants did not allow exploring different nuances of living with HIV. From this perspective, it is recommended to carry out further studies, with greater participation of men and in places where assistance does not occur, guaranteeing discretion and safety to participants, with the possibility of having more meetings or observation with participants.

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