

STIGMA AND BIOGRAPHICAL RUPTURE AFTER HIV/AIDS DIAGNOSIS

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RESUMO

Este trabalho tem como objetivo compreender os modos de vida após o diagnóstico de HIV/AIDS em consequência da experiência da vida com os estigmas e diante da ruptura biográfica. A trajetória metodológica é de natureza qualitativa e exploratória e foi utilizada a entrevista semiestruturada como ferramenta de produção de dados, aplicada em uma unidade de referência para a atenção especializada em uma Capital do Nordeste do Brasil. Foram entrevistados 12 pessoas com o diagnóstico de HIV/AIDS, e a interpretação foi feita por meio da Análise de Conteúdo de Bardin. A pesquisa evidenciou o quanto as pessoas com HIV/AIDS vivem estigmas que os depreciam e que o processo de adoecimento produz rupturas biográficas no seu cotidiano. Concluiu-se que os estigmas atingem não somente os corpos infectados, mas também as relações familiares, profissionais, de autocuidado, inclusive o acesso aos serviços de saúde, assim como os demais ambientes que frequentavam.

Palavras Chave: Assistência Centrada no Paciente; Continuidade da Assistência ao Paciente; Serviços Públicos de Saúde.

ABSTRACT

This work aims to understand ways of life after the diagnosis of HIV/AIDS as a result of the experience of life with stigmas and in the face of biographical rupture. The methodological trajectory is qualitative and exploratory in nature and semi-structured interviews were used as a data production tool, applied in a reference unit for specialized care in a capital in the Northeast of Brazil. 12 people diagnosed with HIV/AIDS were interviewed, and the interpretation was made using Bardin's Content Analysis. The research showed how much people with HIV/AIDS experience stigmas that depreciate them and that the illness process produces biographical ruptures in their daily lives. It was concluded that stigma affects not only infected bodies, but also family, professional and self-care relationships, including access to health services, as well as other environments they frequent.

Key words: Patient-Centered Care; Continuity of Patient Care; Public Health Services.

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1. INTRODUCTION

Acquired Immunodeficiency Syndrome (AIDS) is an illness with a clinical condition that has as its central action on the body the exhaustive combat to the immunological system, caused by the human immunodeficiency virus (HIV). Therefore, it exposes people to an array of opportunistic infections. AIDS had its known origin in the 1980's, although it became a more lethal pandemic in the last stretch of the twentieth century. Its quick evolution was due to the lack of knowledge regarding this pathology and its originator, and it helped build a stereotype of the disease along with the media's stories of its association with the people living with it. Initially, the responsibility for the epidemic was handed over to some social groups, which augmented the prejudice over those infected by the virus and specific populations (Muniz; Brito, 2022).

Regarding the people living with HIV/AIDS (PLHA), social and historical nuances involving the disease should be considered, especially because it builds an important social vulnerability, prejudice and questions regarding the disease (Fonseca *et al.*, 2020). Even with the advances in biomedical sciences and the acquisition of the knowledge that HIV has no preference for a particular social group over another, the stigma over people living with HIV/AIDS paints scenarios with no life perspectives for these people (Campos; Silva; Freitas, 2023).

Nowadays, even after more than 40 years of syndrome spreading, HIV/AIDS has very similar traits in its structure to its initial period. This is because, even after so much time, the epidemic is still viewed by the same optics in which it was viewed when discovered, when dissemination was blamed on historically excluded and discriminated groups. It is not by chance that women, especially the young, black and discriminated are the most affected now. (Ferreira; Darmont, 2021).

By the other hand, there is a way to diminish the viral load to undetectable levels in people living with HIV/AIDS, because an infected person can have better quality of life and reduced symptoms when being treated (Silva; Duarte; Lima, 2020).

It is important to note that, even though nowadays HIV is an infection to which control is possible, the process of falling sick with AIDS is charged with a history of social and moral values, as well as religious matters. The feeling of sadness is the most significant in the diagnosis, and, as it is a chronic disease, the situation can be interpreted like a pain and sadness absorbed to the day-by-day. Therefore, comprehending the aspects involved in the perception of health and the individual capacity to deal with physical and social difficulties can help face the diagnosis. (Cardoso *et al.*, 2023).

Besides the sickness itself, the stigma is a central issue in the process of health and falling ill, especially because this reality keeps on

existing in specific social groups acting as sickening agents, causing psychic and social suffering (Cazeiro; Silva; Souza, 2021). It is of importance to highlight that social exclusion, both of individuals and groups, due to prejudice or discriminatory behaviour can lead to direct health impairment (Silva Junior; Brigueiro; Monteiro, 2022).

In face of this situation, the discrimination for living with HIV/AIDS in all segments of society can constitute a wall to the access to health services, prevention methods and knowledge about disease serological status (Souza; Pereira; Raxach, 2023). Therefore, fear of being judged or shunned is ever present, especially by the view of morality. This can lead to solitary pathways to the caring process, which could affect treatment and antiretroviral therapy adherence directly (Silva *et al.*, 2022).

Thus, as a chronic condition, living with HIV/AIDS can produce biographical rupture, impacting life plans and interrupting existing ways and social interactions of each infected human being, which leads to rough behavioural changes, i.e. changes to subjective projects with thyself and with the world. So, analysing the biographical rupture becomes a perspective taken to structure the effects of the process of falling ill, as well as its experiences after the diagnosis of chronic diseases, and how this can impact the patterns of existence, resulting in reconstruction of life histories. (Cardoso *et al.*, 2023).

In face of all the explored above, this study aims to comprehend the ways of life after the diagnosis of HIV/AIDS, in response to the life experience with the stigma and the biographical rupture.

2. METHODS

This is a qualitative and exploratory study carried out in a health care service considered a city-wide reference for specialized attention to people living with HIV/AIDS, people with other Sexually Transmitted Infections (STI) and Viral Hepatitis in a capital city in the Northeast of Brazil.

The definition of the research participants was according to the following criteria: to be included in the study it was necessary to have HIV/AIDS diagnosis and to be undergoing follow-up in a clinic for more than one year with age superior to 18 years old, besides having a track record of difficulty maintaining treatment or abandonment of antiretroviral (ARV) therapy. On the other hand, having another infectious contagious disease came as the exclusion criteria. The technique of answer saturation was used to define the numbers on the sample. In this technique the number of participants is defined when the researcher realises the aims of the research were achieved during the data production and, so, realises there is no information capable to broaden the scope of the drawn out discussion (Fontanella; Ricas; Turato, 2008). Thus, the total

number of participants was twelve and, to guarantee the privacy of the participants, they will be presented during the text in numerical order according to the chronological order of the interviews and preceded by the term “interview” abbreviated (Int. 01, Int. 02, Int.03, etc...).

To produce the data, semi structured interviews were carried out, following a script, which was designed to direct the collection of data, aiming to contemplate what was initially planned. This script has as a first step the identification of the participant and their sociodemographic characteristics, therefore including the topics age, years of education, marital status, occupation, income, dwelling, family history and constitution. The second step focuses on diagnosis and health care production, containing the topics: time of the diagnosis and treatment, social life impact, HIV versus sexuality, meaning/sense of the diagnosis in one’s life and support network. The third step brings the subject of therapeutic itineraries, with the topics: first place to have sought care, selfcare and family care, reception, ties and relationships with healthcare professionals, light, light-harsh and harsh technologies, meaning and resignification of care pathways and barriers, difficulties and facing offs in the process of falling sick. These topics were explored in the nuances of power relations, health as universal right, geographical, organizational, economic and cultural aspects.

To carry on with the research, the interpretation of the data was done in correspondence with Bardin Content Analysis adapted by Minayo (2014). This analysis starts from the initial conception of the pre analysis, which is composed alongside the beginning of the data production and, consequently, the organisation of the collected material by transcription of recordings, exhaustive and free-floating reading of the materials. Posteriorly, with the connection made with the readings of the materials, the data classification phase starts and is conducted by construction of record units called meaning cores, after these being identified in the data produced. These meaning nuclei were grouped in one of the theme categories: the stigma of living with HIV/AIDS and the biographical rupture after the diagnosis.

After these phases, it is necessary to check the final analysis, which is structured by the connection with what was found in the research and what has been discussed in the scientific community regarding the theme. The research started after the participants signed the Free and Informed Consent Term (FICT) This research was approved by the Research Ethic Committee from Universidade do Estado da Bahia (University of the State of Bahia) under the report number 5.991.828 e CAAE 54898221.4.0000.0057, and respected the Brazilian norms for research with human beings provided by the Resolution number 466/2012 and the norms applicable to Human and Social

Sciences research provided by Resolution number 510/2016.

3. RESULTS AND DISCUSSION

After analyses and in face of the meaning cores constructed, it was possible to establish two categories: The stigma of living with HIV/AIDS and the biographical rupture: life after the diagnosis of HIV/AIDS. These categories will be presented below.

3.1 THE STIGMA OF LIVING WITH HIV/AIDS AND THE BIOGRAPHICAL RUPTURE AFTER THE DIAGNOSIS

Even with the advances in biomedical sciences regarding knowledge about and treatment of HIV/AIDS, which include social and political rights, people infected with HIV need to live with the stigma associated to the process. This affects the way of life in a general way, including what concerns to prevention and care. Therefore, in addressing this subject, one consequently triggers off old and new stigmatizing processes which possess dynamics, scopes, specific and ethical characteristics involved, that demand effective forces to draw out a strategy aiming to combat this mark and its consequences (Cazeiro; Silva; Souza, 2021).

Some studies have been demonstrating how much the family, the partner or the friends are accepted as facilitating units in the process of facing HIV/AIDS. This way, social support becomes of sheer importance for these people to

face the diagnosis and the stress inherent to this condition. Experiences with this support can help maintain mental health and promote independence to the people living with HIV/AIDS. In other words, this support is fundamental to contribute with the adherence to treatment and well-being, which can have a positive effect in the quality of life of these people. Though, a frequent problem amongst people living with HIV/AIDS is the solitude derived from social isolation, prejudice and abandonment (Lavezzo *et al.*, 2019; Patrício *et al.*, 2019). The social abandonment is evident in the following speeches:

But the social mother when I told her I had HIV, she shied away from me [...]. Then, when I was in the hospital he shied away, I did not even want to tell him. He wanted to leave me, and I felt [...], I liked him and I did not want him to leave, then I was a bit depressed, I took several pills, tried to kill myself (I01)

A cousin of mine found out this uncle of ours has, then she said “I don’t want him in my house anymore”, then I said “really, girl? It is not like that”, and she continued “are you crazy? He came here at my home to drink water in a cup” (E02)

It was clear in the testimony of the participants that during the process of falling sick of the people living with HIV/AIDS, very frequently, there is no accepting the illness, and this turns to almost complete rejection by the people in their social circle. This contributes to the development of psychic suffering. Although, it is important to highlight social support and how it could ease the process of managing the

disease and the life of the people living with HIV/AIDS (Lavezzo *et al.*, 2019).

Consequently, upon being diagnosed, in face of the world's perception regarding the infected and the disease, people automatically feel ashamed to let others know about their sickness and, so, they are discriminated, practices associated to bad social images are constructed and absolute discrimination is produced (Garbin *et al.*, 2019). Salvadori and Hahn (2019) reason that the stigma permeates several factors, including people's preference for health care away from home to keep the non-disclosure of their diagnosis to the healthcare professionals, friends, and family. In other words, the fear of having the diagnosis discovered by others, and consequently discriminated, is a prominent factor that affects the treatment. Such situation reveals itself in the testimonies below.

The only thing is the fear of being recognized by someone here where they hand off the medication. Will I meet someone [...], I still have this fear of meeting someone who will expose my life to other people, I have this fear, yes [...] (I04).

I was afraid of coming here because I live here, and people passed and looked, and I hid (I05)

One can perceive from these testimonies that a change of place or the seeking of tending to/treatment in places distant from the patient's residence are strategies found to protect/defend themselves from the stigma and the discrimination by the people closest to them.

Besides, it is clear that the stigma surrounding the people living with HIV/AIDS can keep people from seeking Pre-Exposure Prophylaxis (PrEP) in specialized services because of the fear of being seeing. Therefore, it is evident that a wall is erected by these facts to the access to healthcare, being these factors the most related to non-adhesion to treatment (Silva *et al.*, 2022).

It is important to highlight that a study performed by Campos, Silva and Freitas (2023), found a prevalence of the stigma to people living with HIV/AIDS is around 64% of all the interviewed people in seven capital cities in Brazil. These people revealed to have experience some type of stigma or discrimination for having been infected by HIV, which translates in the fear of having the infection discovered by others and, then, producing bad effects at the working place, that could include even the loss of work value of people living with HIV/AIDS due to a constant vigilance of the colleagues in face of the diagnosis.

Despite the above, studies have presented the impact of the stigma and discrimination in the deterioration of the quality of life of people living with HIV/AIDS in their jobs, associated to the worry of their employers finding out about their diagnosis, leading to their getting fired. This process could impair the continuity of the treatment, because of the need of being discharged from work or presenting of report identifying the sickness (Pereira; Szwarcwald; Damacena, 2019).

Both HIV and AIDS are seen socially as something repulsive, being a source of stigma, which puts people living with HIV/AIDS in inferior categories. HIV/AIDS was shown to be a factor of exclusion from social life for people, which, on turn, has a direct impact on their job (Silva *et al.*, 2022). These moments of anxiety, especially for fears of not being able to work because of the diagnosis, loosing the job by the revelation and any disclosure of information can be observed in the following interviews:

I believe if a person learns, nobody will want to hire a person with HIV. Do you think they would? (I02).

Yes, she said, she arrived in my door and said that I did not need to go anymore, she looked at her girl and said “there is no need of you coming here, because you have your disease and it will pass to my daughter”, so much so that her daughter got a blotch and I was afraid even of using the toilet [...]. She arrived in my house, gave me 50 reais to buy some fruit and after that I never saw her again, she threw me out (I05).

My jobs, I did not find them, because in my jobs, I don't know who, but someone always told me what I had [...]. She sent the girl to tell me “ she does not work here anymore, I don't want this woman here so she does not touch my daughter or me” and I lowered my head and cried. (I05)

It is perceptible, therefore, that because of the lack of knowledge and/or because of discrimination, the employer's dismissal can happen due to considering the people living with HIV/AIDS disseminators of the disease. This prejudice brings up the number of cases of discrimination and stigmatization, especially under the form of dismissal from the job without

reasonable explanation. So, it is evident the problem associated with the significative stigmatization present in the market for the people living with HIV/AIDS (Campos; Silva; Freitas, 2023).

On the other hand, the stigma carries on until nowadays because, regarding AIDS, several prejudices get crossed over and related, especially when related to non-normative sexuality. Therefore, homosexual people, sex workers or people considered promiscuous, who can all be considered non-normative by a hypocritical society, can be elements of the foundation of all the discriminatory theory, besides the correlation with race and its association with the epidemy in black people, especially in countries with populations segregated by race in its majority, in the face of a construction of racial inequality since the slaving of the African peoples (Parker, 2019; Santos *et al.*, 2022).

Both the stigma related to homosexuality and the stigma related to gender are founded on conservative rules and standards, which consider as a sexual deviation and promiscuity practices not seen as acceptable socially by an elite that determine the ways of life a body should take. (Ferreira; Miskolci, 2022). It is evident that the patient's pathways get blocked off by discrimination, prejudice and fear:

She told me “I would rather see you crushed underneath the tractor than see you grow up gay”. Then I took that with me forever. So

much so that I have not spoken to him ever since he said that, understand? This was 20 or more years ago. (I06)

I am afraid to be condemned, of not having the right to live, of not belonging to society, because in reality there is already a subdued condition for me being LGBT. It is like you don't belong to certain social groups because of your gender condition, sexuality or sexual orientation. There is already a strong issue there. Then, with the serological issue this gets som much more violent to deal with (I08).

I had the issue of the homosexuality, they already judge you, then if they see an homosexual person with HIV, there comes the issue of promiscuity, they don't imagine you could be infected by someone who is already on your side, then you don't understand what the person will think [...]. People think that HIV infections come from promiscuity (I11).

Thus, homossexuality is seen as something extremely negative, as well as the distorted vision of society that HIV/AIDS is derived from promiscuity, something that is related to the sexual orientation, creating a social imaginary conditioned to believe that the dissemination and the acquisition of the disease is directly related to the sexual orientation. This puts the sexual orientation as an aspect for fitting into the “risk group”, attributed to people considered socially vulnerable (Ferreira; Miskolci, 2022)

So, people living with HIV/AIDS fear physical violence not because of their disease, but because of their sexual orientation and the colour of their skin. Although, when people are infected by the virus and develop to AIDS, they need to face several challenges in society, besides a social construction that they are

condemned to die, among others. This way, the diagnosis transcends the domain of the clinical and becomes also criminal, rooted in the big scale structural violence of the state (Cazeiro, Silva; Souza, 2021).

A way in for adhesion to treatment among young people living with HIV/AIDS includes aspects of adaptation to life with HIV/AIDS and beginning of treatment. Both the conditions are complex because they permeate problems that involve multiple dimensions to the human being, including the fear of death and the experience of collateral effects of antiretroviral medication (Costa; Meirelles, 2019).

Therefore, there is an incomprehension about the adhesion to treatment being a long process and, above all, difficult to the people living with HIV/AIDS, who can opt to stop treatment for the belief of it being an easier and less painful path. This happens because of the physical manifestations and adverse reactions that the medicine can cause, bringing discomfort and lack of energy, many times interfering even with people's routine and impairing their performance in several activities (Maciel *et al.*, 2019). According to these testimonies, the resistance to medication can be cited as being associated to collateral effects and to the fear of death, suggesting that these aspects are inserted in the experience of the people living with HIV/AIDS:

I took the medicine from them, they said I would feel sick, and have diarrhoea, so I did not take any of them and threw them out and

never returned [...]. Then I took the medicine and went home. Before I got home, I threw it out (I01).

I told him: I will not start, because it is a beginning without an end and I don't want to have any... I don't want to have a relationship with the medication (I09).

Because of this disinformation, false news and a distorted social/historical construction about HIV/AIDS, people living with HIV/AIDS themselves believe that the beginning of the treatment itself refers to the end of life. Considering the media's role was always a strategic action in the prevention of diseases, it exerts a big influence in the social imaginary. Therefore, besides the information, it is also possible to transmit fear and prejudice through the media's contents, which constitutes a complex and multifaceted phenomenon (Costa; Meirelles, 2019). Besides, there are psychological and social factors that make it harder to the people living with HIV/AIDS to get adequately treated, such as the precarity or absence of social affective support, as well as the perception of insufficient support, non-acceptance of the diagnosis and unsatisfactory revealing of information by the patient to the healthcare team (Araújo *et al.*, 2019).

As a result of the HIV seropositive result, ruptures and changes in people's life occur, similarly to what happens in other chronic diseases. HIV appear as a crossroads point in people's lives, which generates the need for permanent care, i.e., it triggers off situations that interfere in new process of relativization with

new relationship networks (Silva; Duarte; Lima, 2020, Santos *et al.*, 2023).

It is of sheer importance to highlight that the discovery of a disease like HIV can bring to the surface a depth of socially imposed existential misery, especially when it mixes with other oppressions, such as racial, economical, sexual and of age (Paquiela *et al.*, 2022). So, according to Freire *et al.* (2021), feelings of hopelessness stem from worries about the disease's evolution, fear of death, insecurity, and pessimism. After the discovery of the HIV infection, feelings of trauma generated by social stigma can rise to the surface in an individual.

Therefore, a rather common feeling to be experienced after the diagnosis can be related to the perspective of death and guilt, which represent the stigma brought by the weight of the infection and bring even more suffering to that person, conditioning a marginalized life (Paula; Mota, 2021). The following interviews reveal information about this reality.

Then we continue, but, for me to accept this in me, it was despair, a world tilting on its axis, because I did not know how to proceed. And It was like we say today, bullying, prejudice, so I was picturing people were looking at me, how it would be for me to get here [...]. Yes, I thought I did not have a life anymore, that I was a leper in earth and wherever I went people would look and say "my God, she has HIV" and I was like this for a while like "my God". Then When I thought about this, I cried alone in the street. Now not anymore (I03).

Then I am talking to different people, there is always someone who looks at me in a way that makes me think they are looking because they know I have the disease. They

don't ask, but then I get [...] (I05)

The fear of rejection, fear of lack of love, fear of lack of embracing, fear of the relationship with other people, and this is very strong, isn't it? This impacts a lot your self esteem. To me, there was a certain fear of deception, of how other people would relate to that. Of the fear people would have (I08).

In face of the revelations above, it is evident the pain of the diagnosis does not come only from the infection with HIV, but also from the social stigma associated with these people by their falling sick. As a result, a big part of the participants of this research seemed to share the judgments and preoccupations about the sickness, which keep them from worrying only about their symptoms, obliging them to divide their worries with the society's prejudices. The phenomenon of getting sick is not an isolate event, as it provokes rupture both of the individual and collective homeostasis, leads to changes in the relational dynamics and warrants emotional reorganization in face of the vulnerabilities generated by the sickness (Lavezzo *et al.*, 2019).

People living with HIV/AIDS need to deal with tension and suffering in a particular way, even though they are deeply influenced by the collectiveness and, consequently, by the historical period they live in. In turn, this could cause a feeling of imminent biological death after a late diagnosis, or a social death after the label takes roots in certain structural beliefs that limit the full exercise of life and citizenship by

the individual (Cardoso *et al.*, 2023).

Some chronic health conditions, such as the infection by HIV can generate life processes difficult to face which heightens the risk of self-provoked violence conditions (Fernandes *et al.*, 2022). In face of this traumatic experience, there is a strong association between HIV/AIDS and depression, this connection being one of the main causes for suicide among people in this community.

[...] I was very depressed, to the point of trying to kill myself one day. I took all the HIV medicines (I01).

And about the suicide matter, I have tried a few times, 4 times, none worked [...] I came to Salvador, I could not see a bridge with cars under, that I wanted to get up there and throw myself from it. Because with poison or medicines It did not work, I thought about throwing myself in front of a truck, but the thought came: go to Salvador, throw myself, kill myself and news was out. Then who died? Fish, son of Soledade. Then the same thing: how did he die? Suicide [...]. Vaz too caught HIV some time after and we went to kill ourselves in a forest in Plataforma. We brought poison and took it together. We said goodbye, but Vaz died, and I did not. So, then, the only person who could accompany me all this time left me alone to bear the burden by myself (I06).

Therefore, people living with HIV/AIDS that possess some type of psychological problem have greater psychic suffering upon being diagnosed. The interviewed patients reported having had suicidal thoughts or attitudes at some time after discovering their having HIV/AIDS. Depression, for example, can affect the interest in social activities, cause irritability, feelings of guilt and low self-esteem, which can all trigger

off thoughts of death and suicide with a frequency (Fernandes *et al.*, 2022).

It is important to note that contemporary lifestyles, pathway choices, trajectories and even interpersonal relations can influence the way people seek solutions to their problems, especially those more complex and demanding more personal or social resources.

In face of the interviews, it becomes evident that the rupture caused by the continuation of life after HIV/AIDS stems from an existential crisis, especially in what concerns to new achievements, dream fulfilment and life goals. All these desires seem to dissolve along the way and the only remaining aspect of the path to be walked becomes HIV/AIDS.

4. FINAL CONSIDERATIONS

In face of all discussed above, we can infer that the historical construction socially produced about HIV/AIDS generates intense prejudice regarding infected people and, at the same time, structures collective misinformation about the disease since its discovery and until today. Because of this lack of initial information surrounded by stigma and prejudice, there is a strong perception when confronted by the diagnosis, which is not entirely related to the virus, but also tied to the possibility of being exposed. This generates isolation and silence, both marked strongly by fear, prejudice and social exclusion. As a consequence, feelings of anguish and sadness are common and present

themselves as strongly related to fear of rejection and of prejudice, resulting in omission of diagnosis and social isolation.

That being the reality, the role of health services in stigma reduction is of sheer importance and goes way farther than performing tests and treatments, but should also include warm reception of all the patients' desires and the reduction of fears presented by people living with HIV/AIDS that may have taken root after their diagnosis and could cause great suffering as well as signify this life moment. For this, spaces are needed for healthcare professionals to share their work methods and knowledge reflecting care and embracing of people living with HIV/AIDS.

Thus, it is possible to conclude that the stigma experienced by people living with HIV/AIDS manifests in different ways and disseminates in a way that has not only affected infected people, but many family and professional relationships, relationships of self-care and of seeking of healthcare services, as well as all the other places these people inhabit.

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