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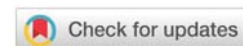
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Research Article

Social representations of elderly people about living with HIV/AIDS

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Abstract

Objective: This study aims to understand the social representations of elderly people about living with HIV/AIDS.

Methods: This is a cross-sectional study, descriptive-analytical, with a qualitative approach and theoretical and methodological support from the Collective Memory Theory and the Social Representations Theory. Conducted with 38 elderly people. It used a questionnaire with sociodemographic data, health conditions, and a script for a semi-structured interview. The data analysis with the support of the QRS NVivo® Software and in the light of Bardin's Content Analysis.

Results: The social representations of elderly persons, about living with HIV were: ruptures, living with treatment and coping with prejudice and the struggle for (over) living: the fear of dying and the spread of the diagnosis.

Conclusion: Social representations of the elderly about living with HIV/AIDS are about living with drug treatment, with the disruptions in their lives, health care, self-care, and pain of social arising from prejudice.

The social and moral burden on the life of a person living with HIV has great impacts, and when it comes to an elderly person, becomes even more accentuated, since the individuals in this age group usually have values and influences from their time that make overcoming such difficulties even more difficult.

As an example of this, a study [1] points out how some of the elderly participants, out of fear of double social rejection, began to adopt a strategy of acceptance affirms that the form of infection was through blood transfusion, which, in their perceptions, would excludes the condition of inappropriate sexual behavior and, thus, reduce the moral judgment.

The education of the elderly about sexuality is still strongly influenced by sociocultural and religious taboos from other times, which tend to conceive the dialogue and the exposure

of subjects related to this theme as something inappropriate, and pejorative, which results in the social judgment of an "old coot" when it is a man and of a vulgar or worthless when an elderly woman [2].

Research [1] that was conducted on 14 elderly (seven women and seven men), aged between 60 and 77 years old verified the confirmation of how the taboo around sexuality and HIV among the elderly in this age group is a reflection of the upbringing modes and culture of their youth.

Thus, it is understood that, due to social pressures, many elderly, silence their condition as a way to face the prejudices of old age and HIV. However, it is important to point out that although this silencing represents a form of confrontation, silencing their condition ends up hindering their adherence to the treatment, considering the manipulation and ingestion

of medicines in the presence of other people, and making it unfeasible to form a close social support network, who could even help the elderly person in their difficulties [2].

It can be seen, therefore, that the concern about secrecy can be accentuated according to the advancing age. However, a study conducted on elderly people living with HIV in Switzerland, found that the discrimination decreased with increasing age [3].

Fear of rejection by family members, friends, and others in their network is a recurring concern among the studies of elderly people living with HIV/AIDS. In a research [4] the factors that negatively influenced the quality of life of elderly people living with HIV/AIDS were investigated, and it was found among these factors, were the concern with confidentiality of their diagnosis, comorbidities and other symptoms, the negative self-image, depression, and rejection.

In another study [5], the elderly claimed that the estrangement of family members and closer people was one of their fears, associated with the lack of knowledge and the taboos of people, about HIV/AIDS and sexuality. In the findings of another study [1], what stands out is the concern of the elderly, and even their own experience of loss of interest in activities that used to be enjoyable, loss of self-care, "paralyzes of desire" and isolation.

All these issues pointed out as a result of HIV/AIDS stigmatization in old age, and even as justified by the Swiss study, elucidate the dangerous posture of silencing, not only because of the complications of later diagnosis but also as a result of a concern with emotional and psychological aspects, that need to gain visibility.

The urgency of this discussion around HIV/AIDS stigma in old age becomes even more necessary, because, as exposed throughout this chapter, there exists a previous process of stigmatization of the elderly population, that added to the condition of HIV, it is accentuated and exerts a double burden. The fragmented assistance that the great majority of times does not provide them integral care, and compromises health prevention, plus the coping strategies, adopted after the diagnosis, submit the elderly people who live with HIV/AIDS, to violent situations, neglect, and self-neglect. From this perspective, this study aims to analyze the social representations of elderly people about living with HIV/AIDS.

Methods

Ethical compliance

This study was approved by the Ethical Committee of a Higher Education Institution, under protocol number 3.394.696, and, after approval, the data were collected, following the fundamental ethical and scientific requirements for research with human beings. The study was performed in accordance with the ethical standards as laid down in the 1964 Declaration of Helsinki and its later amendments or comparable ethical standards.

Kind of study

This is an analytical-descriptive study, with a qualitative approach, based on the Collective Memory Theory and the Social Representations Theory. This study was developed in a Care Center for people with Sexually Transmitted Infections (STIs) HIV/AIDS in the countryside of Bahia.

Participants

The study participants were 38 elders, aged 60 years and older, diagnosed with HIV/AIDS, in treatment at a Care Center for people with Sexually Transmitted Infections (STIs) HIV/AIDS in the countryside of Bahia. The participants of the study were contacted/selected through data collection from clinical records and through semi-structured interviews. The inclusion criteria were: aged 60 years old and older and registered in the reference unit.

In this sense, the exclusion criteria were: elderly people with cognitive deficits that prevented them from participating in the research (rated by Mini-Mental State Examination – MMSE) and elderly people who, after two attempts to contact them for an interview, were not available, were also excluded. After the MMSE application, there were no patients excluded due to their cognitive ability, however, there were seven refusals: three did not accept to participate in the research, and four made the appointment but did not show up, even after two new contact attempts. Therefore, the sample was selected according to the steps described below, in Figure 1.

Instruments and procedures

The data collection tools of this study were used two times, on the same day of application: In the first moment, there was the application of the Mini-Mental State Examination (MMSE), used to exclude elderly people with cognitive deficits. And in the second moment the application of a semi-structured interview script with questions about the disease and the diagnosis.

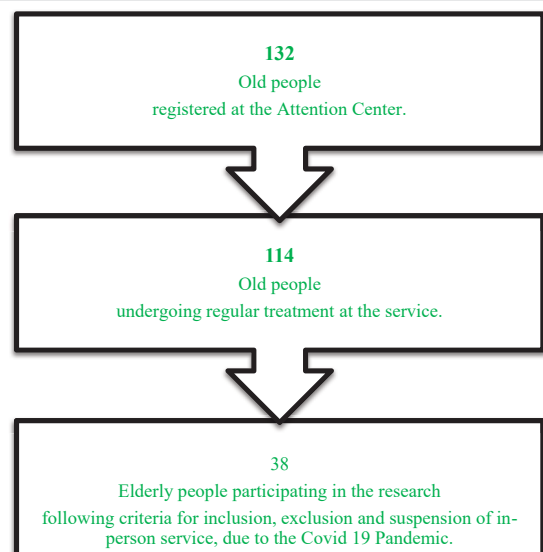


Figure 1: Selection of Elderly People living with HIV/AIDS, registered at the Baiano Care Center, in 2019/2020.

The complete MMSE consists of two sections that assess cognitive functions. In the first section, orientation, memory, and attention, were rated totaling 21 points. In the second section, the ability to name, obey a verbal and written command, and copy a complex drawing, in this case, a polygon, were rated totaling nine points. The total score is 30 points, and the cut-off point is 23/24, which is a score suggestive of cognitive deficit. In this sense, the elderly who presented a cut-off point between 23 and 24 in their scores were excluded from the study.

An initial contact was made with the participants to be interviewed in the waiting room, where they were waiting for care; after approval to participate, the Informed Consent Form (ICF) was handed out and the interviewees' signatures were collected. Subsequently, the collection instruments and the individual interview were applied. The data collection was conducted in a private room at the Care Center, using a mobile device supported by KoBoToolbox software.

Data analysis

Based on the data collected, we proceeded to transcribe the recordings in their entirety. Then, for the analysis and interpretation of the data collected from the interviews, the content analysis proposed by Laurence Bardin was used, with the help of the software QSR NVivo version 12.

For the analyses we chose to list the stages of the technique according to Bardin, who organizes them in three phases: 1) pre-analysis, 2) exploration of the material, and 3) treatment of results, inference, and interpretation. QSR NVivo is a software that allows the import and storage of data. After creating a project in NVivo it is possible to manage the information, through some responsible fields such as source, nodes and codifications, classification, and attributes.

Results

In those living with HIV/AIDS, the Social Representations that emerged reveal the daily reality of living with a chronic disease, where the three most frequent words bring primarily the drug, followed by the disease and the urgency of life perceived in the midst of all these findings, giving way to living.

That said, we present the two subcategories corresponding to this thematic category: (1) Category 1. Ruptures: Living with treatment and facing prejudice; and (2) Category 2. Fighting for (over)living: Fear of dying and the spread of the diagnosis

Category 1: Ruptures: Living with treatment and facing prejudice

From the Social Representations of elderly people living with HIV/AIDS, it is possible to observe through the word clouds of the ten most representative words about this theme, that living with HIV/AIDS means breaking with daily habits and routines, to adapt themselves to live with the drug treatment, the follow-up appointments, and the control tests.

The sum of the elderly people who used the words "remédio" "medicines" and "tratamento" "treatment" corresponds to

50% of the total of the main emphasized word in the word cloud. This fact may be related to the speaking place of these elderly people, all participants in the outpatient follow-up program for people with sexually transmitted infections and HIV, who are regulars in the care and adhere to ART.

I have full vigor, but I know that this problem exists, because I have to come here to get medicines, otherwise, my life would be normal. But it is sad (Carnation 14, 61 year old, common law marriage).

I don't know how to explain. In some things, for example, I think it was even better because I take care of myself because I know that, if I don't take care of myself, I may only have a few years to live. So I do my best to do all the tests that are requested and take the medicine at the right time, all to avoid problems and to be able to live a little longer. I know It is complicated. But, in some things, I felt better, because I'm always at the doctor's, and more attentive to my health (Carnation 18, 67 years old, single).

I don't have the developed virus, because I take medicine; thus, it will not increase, and I live well, and healthy (Rose 22, 81 years old, separated).

Through the narratives, it is possible to observe that, despite the recognition of the interference of the treatment in daily life, positive representations associated with the set of actions that are included in the clinical treatment of those who live with the disease prevail, contributing with expectations of quality of life and well-being, which, consequently distances them from the perceptions of imminent death after the diagnosis and the living with the virus.

The emphasis on self-care and health care, present in the speeches is a milestone in the lives of the elderly in this study, not only with regard to drug treatment, regular medical appointments, and periodic tests, but also with regard to a rupture in the way of life throughout existence, with the need to adapt to new healthy life habits, such as care with food and hygiene, regulars physical activities, quality of sleep, practice of mental health prevention activities, and abstinence of psychoactive substances as alcohol and tobacco. All of this is evidenced in the following speeches:

I take care of my nutrition. I eat well, a lot of vegetables and healthy food, and I sleep well. (Carnation 9, 64 years old, separated).

Well, I do physical activity, walking, running, I'm always practicing some sport, the physical activity has helped me a lot. I also do yoga (Carnation 12, 61 years old, widower).

I take care of myself, I don't keep the disease in my head, because there are some who give themselves away. I don't give myself away. I take care of myself, I like to dress up, and I feel well this way (Rose 15, 61 years old, single).

The negative representations spread by common sense, are the promoters of anguish, the judgment is exacerbated because it is an elderly person living with HIV/AIDS, mainly because it contradicts the social representation of asexuality of this group. All this intensifies the negative feelings and the suffering caused by the stigmatization of the disease, going far

beyond the biological consequences of the diagnosis, as can be observed below:

With HIV you feel humiliated. People don't touch us, that prejudice, I just think the prejudice is bad, because they think, if they touch us, they can fall into contamination (Rose 4, 65 years old, married).

It has changed, because I don't have joy in living, because there is a lot of prejudice, that's why (Carnation 16, 68 years old, single).

Today is boring because sometimes you have to take the risk of being judged, the worst is prejudice, it is not even the disease, because the disease has drugs, the treatment. There are diseases that kill faster, some simple diseases, such as diabetes. Sometimes a person who lives with HIV lives longer, what changes everything is the prejudice (Carnation 34, 64 years old, widower).

Category 2: Fighting for (over) living: Fear of dying and the spread of the diagnosis

For the elderly person, living with HIV/AIDS becomes synonymous with fear: fear of dying, fear of disabilities, and the fear of the spread of their serologic status, as evidenced in the reports below:

I'm afraid of going to bed, if people found out that I have this problem, then now? Then, I'm afraid, that is what I'm most afraid of in my life. Sometimes I feel pain here or there, sometimes I can't stand it, but I resist. But I think what if I stay in bed? I hope God won't let that happen (Carnation 01, 66 years old, separated)

I started drinking a lot more than I was already drinking, you know? It was the alcoholism that increased, and the despair also increased. Fear of dying. Fear like fear of not living long enough to do what I would like to do (Carnation 06, 69 years old, widower).

I'm afraid, actually, is fear of dying, then the day I die... Even though I have already started to pay a health insurance in my city, by the time I die, it's already paid for, then when I die it's just put me in the coffin and bury me (Carnation 25, 62 years old, single).

Is therefore noted that, because of the prejudice and the discrimination that surround the HIV/AIDS condition, the silencing represents an artifice to prevent this stigma from becoming visible. The meaning of secrecy or silencing of the participants of this study can be known in the narratives below:

I keep it in secrecy, they call me a thief and everything but do not speak of this. I'm afraid of what people talk. Because if I say that I have it, wow, then they will say: "He has Aids" (Carnation 25, 62 years old, single).

I do my things like this, hidden, you know? My cocktail I hide. Neither my sister knows this, nor my husband, you understand? Because at that time I was alone, I don't know how I got it, I'm a very reserved woman (Rose 04, 65 years old, married).

So that people don't distance themselves from me, I think like this... I'm afraid of talking and they distance themselves, that's why I don't tell anyone (Rose 17, 62 years old, common law marriage).

It is possible to observe that the discussion revolves around the fear of prejudice and stigmas concerning the disease. The silencing presents itself as a way to give new meaning to life and the way of living, as a strategy of coping and self-care. It means that secrecy has the strength, or potential, to become a protective shield for the psychic, emotional, and social pains explained by the participants of this study.

In this study there were reports that draw attention to the burden of living with silence about one's serologic status, as can be seen below:

I live with the secrecy I live with the secret, that's all that bothers me (Carnation 07, 64 years old, separated).

The biggest trouble is just this taboo, of not being able to talk to people that you are HIV-positive. (Carnation 14, 61 years old, common law marriage).

The hardest thing is to live with people without them knowing. That you want to hide and not show (Carnation 18, 68 years old, single).

Furthermore, the intense investment into the maintenance of the secrecy of the diagnosis can lead to treatment dropout or can make it difficult for the correct therapeutic adherence, for fear of being discovered in the services or by using the ART. In this study, there was a report of discomfort due to exposures in the specialized service, considered as a risk to confidentiality, just as there is resistance to the use of other services of the network, as can be seen below:

We are very exposed here. For example, when we go to get medicines, there are some girls there, then sometimes you get there and there is another person who is a trainee. So it is an exposure that we have to deal with. I've already found the same friends of mine, that I never imagined, that have the same problem, because you know? I don't like this situation, so it's like this thing; you get there and look at each other's faces. I think that this exposure happens (Carnation 8, 66 years old, separated).

I use just this health care here. I avoid going to the health care unit, precisely because I think that if I get there and someone finds out, then the comments start, and I won't accept, that's why I don't look for them (Carnation 16, 68 years old, single).

I use the health care unit, sometimes, when I've a little trouble I go to Dr. xxxx, but he doesn't know, nobody knows (Carnation 36, 64 years old, separated).

Discussion

To live in front of the treatment, fear, prejudice, and keep fighting, despite so many issues to be faced, so many troubles and mistakes that are part of the baggage of the elderly people in living with the virus, where medicines necessary for a quality of life depends not only of technology of the pharmaceutical industry but above all, on the technologies that are the result of the relationship of an operating collective can alleviate or intensify the total pain caused by the disease.

Health care, through balanced nutrition, in quantity

and quality, and practice of physical activities, and other healthy habits are part of the knowledge and values shared by this collective as health representation and prevention of complications and disease progression. All of this is anchored in the reified universe of science, that divulges studies and campaigns, throughout the history of health promotion and disease prevention, about the importance of such behaviors for proper immunity, including the prevention of manifestation of opportunistic diseases responsible by the increase for morbidity and mortality of those who live with HIV/AIDS [6].

Thus, as health care in the context of sickness is synonymous with disease care, or the adoption of a set of actions that avoid the proliferation of the disease or the worsening of the health condition we can infer that such social representations shared by this social group favor not only the wellbeing, but social and psychological and emotional wellbeing, becoming a strategy for living with HIV/AIDS, that deserves emphasis and attention of health professionals, family members, and especially the elderly who live with the virus.

The segregate phenomenon in relation to HIV/AIDS and the confrontations of prejudices are part of this process of ruptures in living with the virus; the lack of information about the disease and societal discrimination can account for the most of grief, pain, solitude, and isolation. The distancing of relationships, including family members, happens as a way of protecting and maintaining confidentiality with the fear of prejudice [7].

Hopelessness and fear give way to resilience and overcoming, which emerge from faith in the supernatural. A study that evaluated the influence of religiosity and faith on adherence to treatment and improvement of symptoms in patients living with illnesses found that, after the diagnosis of pathology, the intensification of faith and the influence of religiosity and prayer favor relief of symptoms and quality of life and brings tranquility and optimism in coping and adhering to the proposed treatment [8].

These psycho-emotional benefits extend to family members who experience the daily struggles of those living with chronic illnesses [9]. Despite the suffering and anguish experienced with the diagnosis of HIV/AIDS, often even disbelief in the real possibility of living with the virus, there is no impact on the faith and religiosity of the participants in this study.

The misinformation, associated with the constructions of common sense representations, anchored in media discourses and the experiences of a past in which access to treatment and preventive resources was scarce because of the need for research and scientific studies, still remains impregnated into the construction of collective knowledge, and it is present in the positions, actions, and also dictates the behavior of health professionals towards the elderly person living with HIV/AIDS [1,10].

The adjectives that marked the HIV/AIDS epidemic in the beginning, were lethal disease, incurable, highly contagious, related to a higher degree of stigmatization, of a specific social

group, considering the social position, the way of contagious and the sexual behavior, characteristics that remain static in the common sense, even if the reified universe, proves the complete absence of these relations through the thousands of published studies [11].

The consequences of such prejudice go beyond the losses not only to those who live with the disease, since it influences the preventive actions, individual and collectives, in the diagnosis that occurs later, the way the disease is faced, and adherence to the treatment. The lack of information exposes the elderly person to a greater vulnerability to infection with the disease, and after the diagnosis, strengthens the suffering caused by the stigmas and prejudices suffered by these, with damages greater than the feared physiological [12].

HIV/AIDS has a powerful symbolic force from the pathological and psychosocial point of view, because of this, when experiencing the diagnosis, a mourning process begins, especially, related to elderly people, who are aware of their own biological declines and in the most of times, get the diagnosis with the manifestations of opportunistic diseases and experience the loss of their health and vitality [11].

The perception of imminent death is enhanced by the fact that it is an incurable disease. In a study carried out with 25 elderly people in a family care unit, with the objective of evaluating their Social Representations of HIV/AIDS, death was in second place among the most said terms, followed by fear and prejudice [13]. In his study conducted in Viçosa – MG [1], with elderly from the Municipal Senior Citizens Programs, investigate, as in the previous study, the Social Representations of elderly people about living with HIV/AIDS, and among the negative representations were on the top: incurable disease, transmissible disease, agony dread fear/horror, danger and death.

For the participants of this study, the announced finitude imposes urgency that makes them reflect on the achievement of dreamed life projects up to programming procedures that involve the end of life, for example paying for the funeral plan. More than that, the fear of what will be the cause of death, is a small sample of the suffering experienced related to the prejudice arising from the spread of the diagnosis, the fear that is capable of anesthetizing physical pain, or physical suffering as a way of minimizing the damage to health, felt with the spread of the disease so that there is no possibility of disclosure of the diagnosis.

The shame and the embarrassment related to the diagnosis of a sexually transmitted disease uncovers the habits and behaviors such as an active sexual life and unprotected sex in old age, which intensifies the feeling of sadness, guilt, and extreme anxiety regarding the possibility of suffering prejudice and social charges at the discovery of the diagnosis of living with the virus [14]. As in the narratives of elderly people in this study, living with HIV/AIDS in old age is to live with a double stigma of being an elderly person who has their values and morals eternalized, threatened by a diagnosis capable of interfering with their social identity, which condemns them to



end their history among their own in this earth as the person who died of HIV/AIDS.

It is possible to observe that this discussion revolves around the fear of prejudice and stigmas related to the disease. The silencing presents itself as a way to give new meaning to life and the way of living, a strategy of coping and self-care. It means that the secrecy has a force or potential, to become a protective shield for the psychological, emotional, and social pains, verbalized by the participants of this study.

However, the silencing can be considered as a factor of greater vulnerability of the elderly people living with HIV/AIDS, since by not activating their social support to face the disease, they may have greater difficulties in adapting and greater loneliness and social isolation [1]. Silence has disorganizing consequences, and can be considered a factor that causes elderly people psychosocial disorders, depressive symptoms, and suicidal ideation [14,15].

It is notorious that, despite the existence of protocols of confidentiality guarantee in the specialized service, the routine, the waiting room, and the frequency of the specialized appointments, routine tests, and even the frequency in the pharmaceutical service can be considered a threat to the well-kept secrecy. The proposal to decentralize the care for people living with HIV, oriented by the Ministry of Health, faces countless challenges in its operationalization, especially in relation to the protection of data in its territory.

In this study, when asked about which health services they use in their care routine, only two people mentioned the use of the Family Health Strategy, despite emphasizing the unawareness of the diagnosis by all the health professionals of the strategy, on the other hand, thirty-six, which correspond to 98% mentioned only the specialized service, for fear of exposure of the diagnosis and prejudice.

A study conducted at the Primary care level, that aimed to analyze the management of the secrecy, of HIV diagnosis and their implications for the care of people living with HIV, brings back daily practices issues, exposed to the risk of breaching secrecy, such as work relationships, relationship with community and relationships with offspring [16,17]. The author concludes by emphasizing the need for actions focused on fighting stigma and prejudice, in order to make the territory a powerhouse in the user embracement of people who live with HIV/AIDS. This is a long way to go until all people living with HIV/AIDS, feel safe to share these places with other users and health professionals there.

Conclusion

In this study, the representational structures and contents of the elderly person living with HIV/AIDS are composed of ruptures in the way of life and with the way of being and being in the social groups to which they belong.

The introduction of antiretroviral therapy in their daily lives brings back the discomfort and the risk of having their diagnosis revealed, is a reference to the disease, both for

family members and friends who are unaware of the health condition of the elderly people, and for them, the daily control and strictness of the drug treatment, rekindle in his memory his serologic status.

However, the habit of including the medication in their daily routine promotes ruptures with old habits of life, such as sedentary lifestyle, inadequate diet, health care, and use of alcohol and tobacco. An improvement process, or awakening to health care begins, as a way to prevent complications and aggravations related to living with the virus.

The silencing of the diagnosis for fear of prejudice, and the need to adapt to new life habits, as a result of the regularity of the appointments, and clinical and drug treatment, promote social isolation and intensify loneliness.

Secrecy, while representing protection against stigmatization, is the greatest difficulty experienced by some in their daily lives. The collective memory of this social group, impregnated with representations constructed since the beginning of the HIV/AIDS pandemic motivated desperation and urgency for life after the diagnosis, due to the prospect of imminent death.

However, the fear of the spread of the diagnosis, reveals itself with the greatest intensity in relation to fear of death, after the chronification of the disease. In this way, some elderly people, experience for decades, the fear of having their diagnosis revealed, and this is expressed even in the situation of the discovery after death, by the fear of having their morals and values threatened by a diagnosis capable of interfering in their social identity, and the person is condemned to end their history among their own here in earth, as the elderly person who died of HIV/AIDS.

In the face of all the questions that make up the study, we can observe, that the way of building the aging, is surrounded by myths, taboos, and prejudice, added to the representations built about HIV/AIDS, is, without a doubt, the symptom that most bothers this social group in their living with the virus.

Confronting the stigma and prejudice must be a struggle for all who live with the elderly person living with HIV/AIDS, family, health professionals, and society, in order to minimize the damages from all social ruptures suffered by this group, and verbalize with so much grief and pain, considered the most serious and difficult to control symptom in their trajectory with the disease.

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