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Social representations of individuals over 50 years old living with HIV

Representações sociais de pessoas acima de 50 anos sobre envelhecer com HIV
Representaciones sociales de personas arriba de 50 años sobre envejecer con VIH

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ABSTRACT

Objective: to analyze social representations of individuals over 50 years old living with the Human Immunodeficiency Virus. **Methods:** qualitative study, interviewing 13 individuals living with HIV, attending by a care assistance facility specialized in infectious diseases. Semi-structured interviews were used to collect data, which later were analyzed by dialectical hermeneutics, by applying the Social Representations Theory. **Results:** after significant reports a few empirical categories emerged: the moment when the diagnosis was disclosed and their feelings afterwards, social representation on aging with Human Immunodeficiency Virus and redefining life. **Final considerations:** the study proved the reality of discrimination against aging people infected with HIV in social interactions as a whole, which requires changes in society's perceptions of this subject, the HIV-positive people themselves and the health system, making possible the emancipation of the individual living with HIV while aging and having quality of life.

Descriptors: Aging; HIV; Social Stigma; Emotions; Nursing.

RESUMO

Objetivo: Analisar as representações sociais de pessoas acima de 50 anos sobre o envelhecer com vírus da imunodeficiência humana. **Métodos:** Estudo qualitativo, realizado com 13 pessoas vivendo com o vírus, atendidas por um serviço de atenção especializada no tratamento de doenças infectocontagiosas. Os dados foram coletados por entrevistas semiestruturadas e analisados pela hermenêutica dialética, tendo como referencial a Teoria das Representações Sociais. **Resultados:** Mediante a relação expressiva dos relatos, emergiram as seguintes categorias empíricas: O momento do diagnóstico e sentimentos da descoberta; Representações do envelhecer com vírus da imunodeficiência humana; e Ressignificando a vida. **Considerações finais:** O estudo demonstrou que existe discriminação referente à infecção associada ao envelhecer no conjunto das relações sociais, o que requer mudanças nas concepções da sociedade a respeito desse objeto, das próprias pessoas soropositivas e do sistema de saúde na emancipação da pessoa vivendo com a doença, visando o envelhecimento ativo e com qualidade.

Descritores: Envelhecimento; HIV; Estigma Social; Emoções; Enfermagem.

RESUMEN

Objetivo: Analizar las representaciones sociales de personas arriba de 50 anos sobre el envejecer con virus de la inmunodeficiencia humana. **Métodos:** Estudio cualitativo, realizado con 13 personas viviendo con el virus, atendidas por un servicio de atención especializada en el tratamiento de enfermedades infectocontagiosas. Los datos han sido recogidos por entrevistas semiestructuradas y analizados por la hermenéutica dialéctica, teniendo como referencial la Teoría de las Representaciones Sociales. **Resultados:** Mediante la relación expresiva de los relatos, emergieron las siguientes categorías empíricas: El momento del diagnóstico y sentimientos de la descubierta; Representaciones del envejecer con virus de la inmunodeficiencia humana; y Replanteando la vida. **Consideraciones finales:** El estudio demostró que existe discriminación referente a la infección relacionada al envejecer en el conjunto de las relaciones sociales, lo que requiere cambios en las concepciones de la sociedad sobre eso objeto, de las proprias personas seropositivas y del sistema de salud en la emancipación de la persona viviendo con la enfermedad, visando el envejecimiento activo y con calidad.

Descriptores: Envejecimiento; VIH; Estigma Social; Emociones; Enfermería.

INTRODUCTION

Over the years, Human Immunodeficiency Virus (HIV) infection has suffered changes in its epidemiological profile(1), and individuals over 50 years old were one of the most vulnerable groups(2). Sexual behavior at that age range and lack of visibility over this issue by health care providers revealed a scenario of sexually transmitted infections (STIs) in that population. This could lead to dangerous sexual behavior, such as unprotected sex, since they do not consider themselves as vulnerable group(3-4).

Despite the HIV expansion in that demographic segmentation, it is still noticeable a limited procedure when it comes to discuss the dichotomy aging and HIV. These individuals faced stereotypes especially when their sexuality had been denied(5). In a social perspective, old age individuals being infected with HIV sounds implausible, because sexual activity has always been seen, erroneously, as a privilege of youth(4), including a literature portraying only aspects related to sexual performance or dysfunctions, and their association with quality of life, giving less emphasis to promoting sexual health and preventing STIs / HIV / AIDS(4,6).

In this regard, stereotypes associated to social representations of those individuals are largely interconnected and can promote actions of social discrimination. Prejudiced social practices aiming individuals over 50 living with HIV come from effects of social constructions, which persist in the representations of growing older and having AIDS(4,7).

Thus, aging with HIV can cause psychosocial impacts including fear of death, being incapacitated and being worried the diagnosis would be revealed to family members, friends and other people from their social circle causing shame, rejection, discrimination and isolation(5), which can be construed as a process of stigmatization(7). That can happen because contradicts the stereotypes specifically linked to old age individuals, causing negative consequences regarding the subjects' identity and experiences, as well as redefines their sense of self and being alive in this world(8).

Overcoming these stereotypes is paramount, because in addition to generating less impacts on their lives, it can show these people different points of view about aging, with less internal conflicts and more possibilities when it comes to living with HIV(9).

In this context, intensifying such topic will turn it possible to recognize particularities of aging with HIV, as well as their representations, repercussions, and feelings. Thus, it will seek to better understand the experience of the reality faced by individuals over 50 years old, as well as the difficulties, to guarantee their place in society and, mainly, aging quality of life(4).

In the perspective to study the problem at hand the following question arose: what social representations individuals over 50 years old living with HIV may have on aging?

OBJECTIVE

The objective is analyzing social representations of aging in individuals over 50 years old living with Human Immunodeficiency Virus.

METHODS

Study ethics

The study was approved by the Research Ethics Committee of the Federal University of Alagoas, following the Resolution No. 466/12 guidelines, according to the National Health Council for research with human beings. The individuals were informed about the survey development and those who agreed to be interviewed signed two copies of the Free and Informed Consent Term, keeping one copy for themselves.

Types of study

This survey was qualitative, and applied Serge Moscovici's Theory of Social Representations' theoretical framework(10).

Study Scenario

The survey was carried out in a specialized public service health care unit for patients living with Stis / HIV / AIDS, in the city of Maceió. This specialized health care unit was created in 1998, providing treatment for patients with infectious diseases in the State of Alagoas, well known to be a reference center for HIV / AIDS, viral hepatitis, tuberculosis, Human T-Lymphotropic Virus (HTLV), Chagas disease and liver diseases. The unit take care an average of 800 patients per month, treating infectious diseases, hepatology, and providing nursing, social worker's consultation, psychology and odontology.

Data Source

During data collection period, 288 individuals with HIV / AIDS were being monitored at the unit: 49 were eligible for survey and 239 were excluded according to the selection criteria, that is, individuals who did not fit the profile, and others who did demonstrate cognitive impairment detected due to the application of the Mini Mental State Examination (MMSE) presenting a cutoff score ranging from 17 to 24, according to their educational level. That way, from all the eligible individuals, 13 HIV-positive individuals over 50 years old were selected after a random order and expediency.

Data Collection

The data were collected using appropriate technique for qualitative studies, so that would cover all items on the form which could help researchers to report important aspects of the research. The interview was conducted by researchers experienced with the interview technique. It took place individually, in a private room, lasting approximately 30 minutes and employing semi-structured interviews. Predefined questions were used, adaptable according to the direction of the dialogue, respecting the interviewee's time. The collection period was from December 2017 to February 2018, following three stages: 1) assessment of the participants' cognitive status, with the application of the Mini Mental State Examination (MMSE); 2) collection of information on social and health characteristics, covering the following variables: age, genre, residence, marital status, education, occupation, time of infection and HIV follow-up, use of antiretroviral therapy, comorbidities and hospitalizations; 3) interview structured according to the object of the study "aging with HIV within social and life contexts".

Data Analysis

The study followed the Consolidated Criteria for Reporting Qualitative Research (COREQ). The information collected was analyzed through the dialectical hermeneutics, which consists of a method capable of giving an approximate interpretation of reality and inserting the individual speech in its context, to understand it from within, and in the historical and totalizing specificity in which it is produced(11).

For the operationalization of the "dialectic hermeneutics" method, were used the stages of data ordering, data classification and final analysis. In ordering the data, all the information obtained was mapped, through the transcription of the recordings, re-reading of the material and organization of the reports. In the data classification phase was carried out a transversal reading of the communication corpus, establishing the relevant information for the construction of the categories(11). Ultimately, in the final analysis, articulations were made between the categorized data and the theoretical framework, which made it possible to compare ideas among people's representations and tried to obtain answers to the proposed objective.

To protect the participants' identity, it was decided to identify them with the letter "R", from the word Representation, along with the sequential number of the interview (R1, R2, R3 ...).

RESULTS

Description of study interviewees

Five women and eight men participated in this study, ages ranging from 50 and 77 years old; eight individuals mentioned having up to 7 years of schooling, while two have never studied and three reached up to 10 years or more. The group of interviewees was formed by single, married, divorcees and widowers. The majority lives in urban areas, originally from the capital city of Maceió, others came from small suburb areas, while two persons came from the rural area.

The period of becoming aware of the diagnosis varied from 2 months to 17 years. The majority was being treated with antiretroviral drugs, with one exception: one interviewee reported knowledge of the infection but didn't start the treatment yet. Among the comorbidities, many reported gastritis, hypertension, diabetes mellitus and osteoporosis. After diagnosis, only one participant reported hospitalization due to a stroke.

From the analysis of the information, three categories were elaborated: "The moment of diagnosis and feelings of discovery"; "Social representations of aging with HIV" and "Redefining life".

The moment of diagnosis and feelings about the discovery

In this category, when it comes to serological condition, the interviewees remembered the moment they learned the diagnosis and mention the impact they experienced and a persistent association of the infection to death.

> *As soon as I learned the news, I felt I was going to die. It's awful when someone hears such news. I thought I was going to die, there was no treatment available, and I would not be able to take care of myself.* (R7)

> *Then, I used to think I was going to die. I was depressed and cried all the time; I cried everywhere.* (R12)

> *I don't know how long I'm sick, how much time do I have to live. people say maybe ten years, right, before my time comes.* (R8)

The majority felt the infection brought up feelings of sadness, shame, and disbelief.

> *I'm depressed. Really sad. It's tough to think about it.* (R1)

> *I didn't know such thing even existed; I was even doubtful. I was ashamed because of my children; I did not expect this and suddenly discovered I had it* [infection.] (R13)

Therefore, that representation establishes further boundaries for the individual.

> *Now you realize things have change, your life has changed. You can't have a good time anymore, have a beer, date, everything is forbidden.* (R2)

Social representations of aging with Human Immunodeficiency Virus

Considering the category of representations of aging with HIV, the reports showed comparisons regarding the limitations that longevity causes in the social imaginary.

> *I know that at certain age the body is not the same. Soon my life will be over.* (R6)

> *When I was younger, I enjoyed my life: drinking and having a good time. But when the individual grows older why bother to go to a party? I'm fine and short of 3 years to complete 80 years old. After seventy everything is a blessing, right?* (R13)

This perception that HIV infection could be used as another potential to way to look at themselves as more vulnerable to other illness.

> *I only know* [for sure] *this disease has brought a lot of troubles to my life. The doctor told me it must have been the cause of my osteoporosis.* (R3)

> *Will I grow old? Will I become debilitated? How can I remove this virus from my body? It's frightening. Anything, such as a little symptom, likes coughing, could be pneumonia.* (R5)

When asked about social representation in the context of aging with HIV, the statements complemented each other mentioning experienced or imagined prejudice.

> *Society prejudice is the main issue, which is the strongest barrier imposed on people living with HIV. I was target of prejudice; it was terrible! It was awful!* (R4)

> *Imagine I become ill and people walk away from me trying to keep their distance. It's awful. Feels like you were dead, you didn't belong to this world anymore. That's why I decided to hide it [being seropositive] from everybody.* (R8)

In this perspective, when people started to think about this issue, they expressed feelings of frustration and fear.

> *I remember my best friend stepping into my house ordering my daughter around, taking everything from me, such as bathroom, clothing, … I was devastated! Couldn't stop crying. Should I be treated like someone who has got tuberculosis? I was weak, almost dying, from chickenpox. At that moment I prayed to God, in tears, asking him to spare my children and my granddaughters*. (R12)

Fear of prejudice is one of the main reasons for concealing the diagnosis.

> *I guess people enjoy making comments, such as "look at the old man, he should be ashamed of himself."* (R13).

At the same time, the idea of becoming a target of ridicule in the society was also a predominant factor in their speech.

> *Superficially people's reaction appears to be normal, but I can sense a hidden prejudice. I can tell by the look in their eyes, the small talk and giggling*. (R4)

> *I go out on the streets, thinking people are making fun of me "an old person looking like a fool". He is crazy.* (R3)

The motive behind this perception is that sexuality has been pointed out as a deviation from normality, and the individual is embarrassed to admit having an active sexual life.

> *Nobody views it as normal.* (R3)

The fact that Health care services didn't notice the vulnerability of this age group in acquiring HIV was pointed out.

> *I've consulted many specialists to find out what was going on with me; I got a clean bill of health, but at the end of the day, after a long time, they wanted to try another exam. That's how I found out I had the disease, which, by the way, never crossed their minds*. (R13)

The interviewees expressed the existence of a symbolization zone incorporated to the condition of being seropositive living HIV/ AIDS, which were expressed by comparative elements.

> *We always carry a poster, like a stamp ... People with HIV always become target of prejudice.* (R4)

It's possible to observe the symbolic character of these representations in people who reported feeling diminished only to their disease.

> *Do you know the old cautionary tale about individuals who had leprosy, and folks on the streets kept shouting "leper, leper", and people with contagious diseases had to be kept at bay*? (R5)

They even compared themselves to someone who commits illegal conducts.

> *It's like a thief, he stole your house here and then he's going to steal there.* (R2)

In this way, people found themselves marked by a contagious disease and felt that, according to the social imaginary, they should be kept at a distance, segregated from the others.

> *People do not want to deal with individuals with this disease, because they believe that by just talking to someone it could be transmitted*. (R7)

> *In my opinion if people know about it, they'll walk away, because they believe it could be caught during a conversation*. (R6)

The dimension of these representations makes it easy to notice that the participants reproduce the same behavior in the face of the disease.

> *I got this damn infection after 10 years living by myself; then I decided to start dating and this is the outcome.* (R10)

> *I decided to date someone without knowing he was sick, because if I had known, I would never date him*. (R7)

> *Only Jesus can help someone living with such a disease. Without faith in God, the person can make something stupid*. (R1)

As a result of the HIV infection and aging process, many of the interviewees became isolated. The statements show they are restricted to their homes and present submissive behavior, which can be understood as something more suitable to the new imposed condition.

> *I used to go out, but today I live in isolation at home because of my illness. When I'm preparing myself to go to the doctor, I feel sick, worried, unable to sleep. Nowadays, the worst thing that could happen to me is to leave my home. In my mind everybody* [society] *knows.* (R3)

> *And you can feel yourself aging and you isolate yourself from society. I spent almost a year without talking to my family, less alone staying in the same room. I could only eat and sleep. I used to be a healthy guy, but after that I became ill.* (R2)

Resignifying life

When it comes to the category resignifyng life, the following statements, despite the chronic aspect of the infection, showed that the treatment was enough to keep the situation under control.

> *There is a treatment available, and if you follow the antiretroviral therapy correctly the viral load will become undetectable*. (R4)

Interaction with other people living with HIV contributed to dealing with the diagnosis.

> *I joined some meetings with people living with HIV, which helped me a lot. I witnessed people who had been sick longer than me and continued to be well and healthy*. (R5)

Among the strategies sought to resignifying life spiritual assistance was mentioned by the participants as a support for coping with the representations experienced while aging with AIDS.

> *Going to the church does help me a lot. Sometimes I feel miserable at home, so I go to the church, and when I come home, I'm already feeling better, happy, smiling* ... (R7)

> *I like to attend mass, go on a pilgrimage. I always hold onto the Word of God*. (R13)

DISCUSSION

The characteristics of the interviewees were the same as those of other studies with people over 50 years old living with HIV/AIDS, showing a predominance of males, low education, residing in urban areas and using antiretroviral therapy(12-14).

Considering the interviewees' statements about the moment of diagnosis and feelings of discovery, stood out elements related to shame, sadness, and disbelief. These representations show the emotional burden those patients must endure, whereas the notion of shame can be interpreted as the stigmatizing side of the disease(9).

When facing the HIV seropositivity, participants found themselves threatened with a life and death situation and look at the illness as a deadly sentence, which is very different from the current scenario of a controllable chronic disease, because when adhering to treatment the patients have the same life expectancy of the general population(15-16). Representations of that fear can be somewhat be conquered by searching for information after the revelation of the diagnosis and promoting daily care activities(4).

In this perspective, the externalization of the aging process associated with the infection was attached to several implications, where many interviewees stated they were feeling more vulnerable to become sick. In this case, the uncertainty regarding the prognosis and the progression to AIDS, as well as the presence of other comorbidities caused by HIV infection, generates, frequently, representations of insecurity, especially in advanced age individuals(12).

Moving on to the category of representations of aging with HIV, some constant and similar elements appear in the interviewees' statements regarding fear or the very experience of prejudice and biological and psychosocial repercussions caused by it. As a result, fear and embarrassment are expressed by them when they are led to think about the condition of the aging process with AIDS in the society(16). Seeking to safeguard themselves against negative consequences of experiencing this daily process, most participants opted to hide the infection, even from their own family members, which shows the social and moral burden on the person with the infection, which seems to increase when associated with the aging(4,12).

The misrepresentation of elderly people as nonsexual and free from contamination by HIV and other STIs was shown to be crystallized in the participants minds. Furthermore, the attitudes of older people towards HIV do not always come with the perception that they are likely to become infected since they are not viewed as sexually active people that they can experience freely relationships, without needing to protection. This sometimes also leads them to neglect prevention methods(5,12).

Due to the lack of visibility, the topic of sexuality in this population group has been widely discussed in the scientific community(4,6,17). Evidence points out that people who are in the process of aging do not have a fully and freely sexuality, since they are being exposed to the oppressive culture of society and family(18). Thus, the influence of the social scenario regarding repression stereotypes is noted as being the result of representations of behaviors of previous centuries(16).

Interviewees highlighted great fear of being ridiculed by society. So, when evaluating elderly patients' conceptions currently living with HIV the study revealed that these individuals manifested representations such as to have AIDS at this moment of life was shameful and disappointing and it could be a sign as promiscuity(4).

Still in this sense, the interviewees reported suffering, either in the present or in the past, some kind of prejudice after the diagnosis, by relatives, friends or people close to them; even those who have decided to hide their HIV-positive condition, although they do not suffer prejudice directly, feel bad about the way society perceives a person living with HIV. The attitudes of discrimination directed at people in the process of aging who live with HIV show representations regarding the fear of contagion, the immorality that is supposed to be related to this infection and the threat to life caused by the syndrome(5).

As implications of these representations, there is the social isolation observed when adopted resigned behaviors, which was mentioned by the interviewees as something expected and natural due to the infection and the advancing age. This isolation comes from the fear of suffering discrimination and prejudice; as a consequence, these individuals opt for secrecy about their health condition(17).

At the same time, spiritual practice was the main way to help interviewees to cope with difficulties experienced because of the diagnosis of AIDS. This finding confirm other studies that suggested that spirituality is an important aspect of resilience for individuals aging with AIDS(19).

Therefore, it was noted that when having new life expectations in the face of the syndrome, a new world was presented to those people, who seek to better understand the disease, as well as forms of treatment, which contributes to the process of acceptance and overcoming many fears experienced. This understanding is an element to facilitate the development of skills to manage self-care(20).

Study limitations

The study presented some limitations concerning the complexity of approaching the interviewees, since it is a theme viewed by society with prejudice and stigma. However, the researchers tried to minimize those limitations through effective listening and embracing the interviewees, showing how much their testimonies could help in building a critical thinking and changing the ways of viewing the topic. Furthermore, the study was restricted to one reference unit, which at the time of data collection met the object proposed for the study.

Contributions to the Nursing field

Given the insertion of nursing in the dynamics of care in all life cycles, including in the aging process, the recognition of these representations is of paramount relevance to the profession, since it can offer nurses subsidies to rethink their assessments during patient care. Thus, we seek to provide venues that favor dialogue and address issues related to the multiple dimensions that involve people with HIV in their process of aging living in our society, such as sexual health and awareness about HIV / STIs and ways of prevention, in order to break stigmas and stereotypes that hinder comprehensive care.

FINAL CONSIDERATIONS

The social representations about people over 50 living with HIV/AIDS portrayed in this study revealed some beliefs, interpretations and a system of symbolization established to explain the social object. Those representations were evidenced by conceptions related to stigmas, prejudices, insecurity, and segregation. Thus, it is revealed, from the participants' imagination, that AIDS assumes dimensions of a syndrome, being represented as a social phenomenon of great proportions that, associated with aging, causes significant impacts on the life of the seropositive individual, both in their insertion and social integration as well as interpersonal relationships.

According to the above, the pursuit for strategies aimed at optimizing the relationship of seropositive people in the social sphere, with special attention to those over the age of 50, becomes essential, considering the double discrimination that they often face in the confluence of social relations. Therefore, changes are needed in society's perceptions about this subject, in the HIV-positive individuals themselves and in the health system, whose responsibility is vital in the emancipation of the individual living with HIV / AIDS, aiming actively ageing and with quality of life.

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