REUFSM
REVISTA DE ENFERMAGEM DA UFSM

ISSN 2179-7692
Open access

Rev. Enferm. UFSM, v.12, e39, p.1-18, 2022 • https://doi.org/10.5902/2179769268006
Submission: 10/19/2021 • Acceptance: 6/21/2022 • Publication: 8/16/2022

Original Article

Social representations of the Human Immunodeficiency Virus among HIV-positive adults*

Representações sociais de adultos soropositivos sobre vírus da Imunodeficiência Humana e Aids

Representaciones sociales de adultos VIH positivos sobre el Virus de la Inmunodeficiencia Humana

Rebeca Coelho de Moura Angelim[I], **Sérgio Corrêa Marques**[II], **Denize Cristina de Oliveira**[II], **Regina Célia de Oliveira**[I], **Daniela de Aquino Freire**[I], **Fátima Maria da Silva Abrão**[I]

[I] Universidade de Pernambuco (UPE). Recife, PE, Brasil
[II] Universidade Estadual do Rio de Janeiro (UERJ). Rio de Janeiro, RJ, Brasil

* Extracted from the thesis "Coping with living with HIV from the social representations of hiv-positive adults", Associate Graduate Program in Nursing, University of Pernambuco/State University of Paraíba, 2019.

Abstract

Objective: to identify the social representations of the Human Immunodeficiency Virus (HIV) and the Acquired Immunodeficiency Syndrome (AIDS) among HIV-positive adults. **Method:** exploratory-descriptive field research, with a qualitative approach, based on the Theory of Social Representations, carried out from 2017 to 2018, in the city of Recife, Pernambuco, Brazil, applied 129 questionnaires of free evocations with adults living with HIV and 30 semi-structured interviews. Prototypical and lexical analysis was used. **Results:** Results: we observed representational contents linked to the beginning of the epidemic, such as prejudice and death, reflecting on their historical basis, as well as contents related to a perspective of normality of the disease. **Conclusion:** it was demonstrated the existence of a process of change in the representations, initially linked to death, but later, a view of normality, probably as a consequence of living with the disease, through the new context that allows greater survival.

Descriptors: Social Perception; HIV; Acquired Immunodeficiency Syndrome; Adult; Nursing

Resumo

Objetivo: identificar as representações sociais de adultos soropositivos acerca do Vírus da Imunodeficiência Humana (HIV) e da Aids. **Método:** pesquisa de campo, do tipo exploratóriodescritiva, com abordagem qualitativa, fundamentada na Teoria das Representações Sociais, realizada de 2017 a 2018, na cidade do Recife, Pernambuco, Brasil, aplicados 129 questionários de evocações livres com adultos vivendo com HIV e 30 entrevistas semiestruturadas. Utilizou-se da análise prototípica e lexical. **Resultados:** observaram-se conteúdos representacionais atrelados ao início da epidemia, como preconceito e morte, refletindo sobre a base histórica destes, como conteúdos relacionados a uma perspectiva de normalidade da doença. **Conclusão:** demonstrou-se existência de processo de mudança nas representações, inicialmente ligadas à morte, porém, posteriormente, visão de normalidade, provavelmente como consequência da convivência com a doença, por meio do novo contexto que possibilita maior sobrevida.

Descritores: Percepção Social; HIV; Síndrome de Imunodeficiência Adquirida; Adulto; Enfermagem

Resumen

Objetivo: identificar las representaciones sociales de adultos VIH positivos sobre el Virus de Inmunodeficiencia Humana (VIH) y el Síndrome de Inmunodeficiencia Adquirida (SIDA). **Método:** investigación de campo exploratoria-descriptiva, con enfoque cualitativo, basada en la Teoría de las Representaciones Sociales, realizada de 2017 a 2018, en la ciudad de Recife, Pernambuco, Brasil; se aplicaron 129 cuestionarios de evocaciones libres con adultos que viven con VIH además de 30 entrevistas semiestructuradas. Se utilizó análisis prototípico y de léxico. **Resultados:** se observaron contenidos representacionales vinculados al inicio de la epidemia, como el prejuicio y la muerte, reflexionando sobre su base histórica, así como contenidos relacionados con una perspectiva de normalidad de la enfermedad. **Conclusión:** se demostró la existencia de un proceso de cambio en las representaciones, inicialmente ligado a la muerte, pero luego, una visión de normalidad, probablemente como consecuencia de vivir con la enfermedad, a través del nuevo contexto que permite una mayor supervivencia.

Descriptores: Percepción Social; VIH; Síndrome de Inmunodeficiencia Adquirida; Adulto; Enfermería

Introduction

In the world, by the end of 2019, there were 38 million people living with Human Immunodeficiency Virus (HIV).[1] Since the beginning of the Acquired Immunodeficiency Syndrome (AIDS) epidemic, 1980, in Brazil, until June 2020, 1,011,617 cases had been registered in the country, and the highest concentration was observed in individuals aged between 25 and 39 years, in both sexes, of which 52.1% correspond to male individuals.[2] The highest incidence is concentrated in adults, an age group characterized by the transition from school to the job market and changes in family, affective and sexual relationships.

HIV/AIDS is still a disease fraught with stigma and prejudice, which contributed to the construction of the first social representations and still nowadays directly interfere with the quality of life and coping of people living with the virus.[3]

In addition, the current scenario shows that HIV is far from over, at least not before 2030, given that many people have not yet discovered their seropositive status.[4] However, despite the AIDS epidemic having spread throughout the world in an unimaginable way for the time, on the other hand, significant advances and achievements have been obtained with the support and struggle of Non-Governmental Organizations, such as programs for the free and universal drug dispensing for the treatment of AIDS and opportunistic diseases, distribution of condoms, specialized assistance services for HIV/AIDS, among others,[5] aspects that had a direct influence on the transformation of representational content about the virus throughout the epidemic.

Thus, seeking to understand the epidemic, based on the history of this disease, the evolution of the profile, and the representations built in the coping and in experiences of living with HIV, is still relevant in the current scenario of the pandemic and in the context of health and nursing care, since apprehending the perception of people with HIV in relation to the world involves information constructed from everyday life, and may, in a way, be influenced by attitudes, beliefs and values that were socially structured.[6]

It should be noted that nursing has been increasingly dedicated to patients living with HIV, developing actions, among which it aims to amplify the knowledge about practice and health care, performing comprehensive care that involves physical issues, psychological and emotional, a challenge for the quality of care for these patients.[7]

In this way, knowing the social representations of HIV/AIDS makes it possible to bring greater understanding of the conceptions about the health-disease process, based on common sense, in addition to understanding the relationships between representations and the modes of conduct of people living with this condition, which is important for health policies and the planning or evaluation of health practices.[8] Thus, the objective was to identify the social representations of HIV and AIDS among HIV-positive adults.

Method

Field research, exploratory-descriptive, qualitative, based on the Theory of Social

Representations, on the structural approach; approach defined by Jean-Claude Abric who formulated the Central Core Theory, and the procedural approach, developed by Denise Jodelet. For Moscovici, social representation is a particular type of knowledge, whose function is the elaboration of behaviors and communication between individuals.[9]

The theoretical perspective of the structural approach emphasizes the cognitive-structural dimension, in which representation is an organization of meanings that works as a system of interpretation of reality that governs the relationships of individuals with the physical and social environment, which determines behaviors and practices.[10] The elements that constitute the representations, such as knowledge, images, beliefs, opinions, practices and attitudes of a social object, such as HIV/AIDS, are structured in a model organized by a central and peripheral nucleus.

In the procedural approach, social representation "is a form of knowledge socially elaborated and shared, having a practical objective and contributing to the construction of a common reality to a social group".[6:36] In this way, it makes it possible to inform about the world around us, through the social relationships of people.

Therefore, it is important to understand the phenomenon, the psychosocial approach, through the theory of social representations, in procedural and structural approaches, seeking to identify the problem from the perception of people living with HIV/AIDS.

The study was carried out in two Specialized Assistance Services for HIV/AIDS, linked to University Hospitals, located in the city of Recife. These institutions are a reference in the care of the adult population of Pernambuco, Brazil. The participants were adults living with HIV/AIDS, in outpatient follow-up at the Specialized Assistance Services included in the research. Thus, 129 people living with HIV were selected, using the Convenience Sampling technique, to compose the total number of research participants, according to the order of outpatient care.

The inclusion criteria established were: age between 18 and 59 years old - adults were chosen, considering the epidemiological profile; being of both sexes - for favoring the knowledge of the object regardless of gender; with a positive serological diagnosis for HIV/AIDS for at least one year, a fundamental factor in the process of elaborating practices on the representational phenomenon, in addition to the crystallization of representation about a certain object. People with a history of mental disease described in the medical record were excluded from the study.

Data collection was performed by the author and Scientific Initiation Scholarship holders. Data collection was completed with all participants (129) of the survey answering the sociodemographic and free evocation questionnaire (structural approach). This number is justified because, according to researchers focused on studies related to social representation, it is favorable for apprehending the phenomenon. In order to participate in the semi-structured interviews, an invitation was made, after the application of the questionnaires, and a total of 30 participants were sought, as this is the considerable minimum for deepening the process of building the social representation of a given object in the procedural approach.[11]

Participants were approached on the day of the outpatient consultation at the study hospital, where data collection and interest in participating were explained in detail. The interviews were carried out in a private room, in a calm and individual environment, in the hospital unit. A digital device was used to record all the content, which lasted a mean of 30 minutes, without external interference.

Data collection took place in the first half of 2017 and the first half of 2018, through two techniques: free evocation of words and semi-structured interview. For the free evocation technique, a form guided by the following questions was applied: cite the first five words or expressions that come to your mind when talking about HIV/AIDS. Then, participants were asked to list the words/expressions in order of importance, from 1 to 5, with the first being considered the most important and the fifth the least.

In the development of the interview, a script was used that addressed the social context, reactions to seropositivity and coping with HIV, axes that led the procedure, seeking to identify the contents and dimensions present in the social representations of HIV/AIDS. The identity of the participants remained confidential and the names were replaced by the letter I (representing the word interviewee), followed by the interview number (Ex.: I1).

For data analysis, the *Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires* (IRAMUTEQ) software was used.[11] The option for using this software was based on the recognition of this tool in research for studies with a qualitative approach and social representation. The software allows the analysis and interpretation of speeches, research questionnaires and texts, formed by the set of evocations obtained in a structured question and/or through an inducing term referring to the object of study.[12]

To organize the product of free evocations, the Microsoft Office Excel software was used, in which the words or expressions were inserted in columns, according to the order of importance given by the participants. Subsequently, the data were submitted to the IRAMUTEQ software to perform the prototypical analysis, also called evocation or four-house analysis, containing four quadrants, displaying the central and peripheral elements of social representation. It is a simple and effective technique, developed for the structural characterization of a social representation, based on the criteria of frequency and order of evocation of words.

In order to process the data resulting from the interviews, the technique of lexical content analysis was adopted. This type of analysis uses the words found in the text, through statistical inference. Words are grouped according to meaning and initially systematized into text segments for later interpretation. No specific content analysis procedure was used. The text segments were used to exemplify/specify the semantic contexts of the evoked words present in the four-house box.

To ensure the ethical principles of research involving human beings, the study respected the Resolution nº 466, of December 12, 2012, and was approved on April 10, 2017, by the Research Ethics Committee of the institution where the study was carried out, according to the opinion nº 2,009,411. In addition, the Informed Consent Term was used to provide participants with knowledge about the research and obtain acceptance.

Results

A total of 129 people living with HIV participated in this research, most of them aged between 40 and 44 years (23.26%), male (55.81%), heterosexual (71.32%), with incomplete elementary school (40.31%), and single (52.71%). Regarding the time of diagnosis, most of them had been diagnosed between 5 and 9 years (26.36%), as shown in Table 1.

Table 1 - Distribution of sociodemographic data, Recife, PE, Brazil, 2018 (n=129).

Sociodemographic data	N	%
Age (years)		
18 - 24	2	1.6
25 - 29	7	5.4
30 - 34	12	9.3
35 - 39	23	17.8
40 - 44	30	23.3
45 - 49	19	14.7
50 - 54	22	17.0
55 - 59	14	10.9
Sex		
Male	72	55.8
Female	57	44.2
Sexual orientation		
Heterosexual	92	71.3
Homosexual	25	19.4
Bisexual	8	6.2
Other	4	3.1
Schooling		
Illiterate	5	3.9
Incomplete fundamental school	53	40.3
Complete fundamental school	8	6.2
Incomplete high school	13	10.1
Complete highs school	36	27.9
Incomplete higher education	7	5.4
Complete higher education	6	4.7
Post-graduate degree	2	1.5
Marital status		
Married	30	23.3
Single	68	52.7
Separated/Divorced	10	7.7
Widowed	6	4.7
Other	15	11.6
Diagnosis Time		
6 months – 11 months	8	6.2
1 year – 4 years	27	20.9
5 years – 9 years	34	26.4
10 years - 14 years	32	24.8
15 years – 19 years	19	14.7
20 years or more	9	7.0

For the prototypical analysis of the free evocations, after preparing the corpus and inserting it in the IRAMUTEQ software, the following parameters were defined for the construction of the four-house box: minimum frequency of eight words, limit frequency (mean frequency) equal to 15 and mean of the mean evocation orders (rang) equal to

2.9 which corresponds to the mean of the general position of the words evoked.

At the end of the data processing, the software generated the four-house box, according to Box 1.

Box 1 - Prototypical analysis of evocations to the inductive term “HIV/Acquired Immunodeficiency Syndrome” among people living with HIV. Recife, PE, Brazil, 2018.

	<=2.9			>2.9		
>=15	**Terms**	*f*	**Rang**	**Terms**	*F*	**Rang**
	Prejudice	32	2.7	Medicines	29	3.5
	Death/dying	24	2.1	Care	23	3
	Sadness	19	2.1	Treatment	19	3.4
	Normal disease	19	2.4	Life/living	16	3.4
	Cure	17	2.2			
	Fear	16	2.8			
<15	**Terms**	*f*	**Rang**	**Terms**	*f*	**Rang**
	Disease	12	2.3	Prevention	12	3.3
	Bad	8	2.2	Discretion	11	3.8
	It has no cure	8	2.1	God	11	3.1
	Fight	8	2.8	I live a normal life	10	3.1
				Condom	9	3.6
				Children	8	4.1
				Family	8	3.9

Through the four houses, the possible central, contrast and peripheral elements of the social representation of HIV/Aids among adults living with the virus were evidenced. Thus, in Box 1, we can observe the following distribution of the words/expressions, listed below, by quadrant.

In the upper left quadrant are the words **prejudice, death/dying, sadness, normal disease, cure and fear**, considered the possible central elements of the representation, which, for having the highest frequencies and low mean order of evocation (rang), allow us to affirm that they are stable and constant elements. The word prejudice was the most evoked (27), followed by the words death/dying (19) and sadness (17), which were the most readily evoked (rang = 2.1).

In the lower left quadrant are recorded the words, **disease, bad, it has no cure and fight**, being the contrasting elements, which have low frequency and were recalled more readily than the other elements. This quadrant contains negative elements which mostly reinforce the notions present in the central nucleus. However, the expression **it has no**

cure is an exception, showing a positive term, which may be reinforcing the expression **normal disease**, also present in the central nucleus.

In the upper right quadrant, called first periphery, are the words with high frequency, but which were not readily evoked: **medicines, care, treatment, and life/living**. The lower right quadrant is reserved for the words that obtained low frequency and high mean evocation order, that is, they were evoked belatedly: **prevention, discretion, God, I live a normal life, condom, children, and famil**y.

Global analysis of the contents of the representation shows that the three dimensions described by Moscovici are present in the structure. Thus, it is observed that the information dimension, which refers to the knowledge, concepts and ideas that the group has about the object, was the most expressive, composed of the words: normal disease, cure, medicine, treatment, care, disease, it has no cure, prevention, condom. The imagery dimension was expressed in the words death/dying, children and family, life/living, and God. The attitudinal dimension, which is related to affections and judgments, ending up explaining the global orientation in relation to the object of representation, was revealed in the words prejudice, discretion, bad, fight, I live normal, sadness, and fear.

Most of the contents present in the upper left quadrant expressed negative positioning in relation to HIV/Aids, and only two positive attributes. The negative aspects were linked to psychosocial and affective issues, expressed by the **words prejudice, death/dying, sadness and fear.**

This evidence was also found in the speeches, especially regarding the reception of the diagnosis, which occurs in a traumatic way, with feelings of concern, fear, anger, denial and sadness.

> *It doesn’t matter whether we stay alive or die, it’s sad, because a lot of people move away, get scared, abandon us.* (I14)
> *Sad, when we find out, it’s terrible, even because my family doesn’t know, nobody knows because of prejudice, because a lot of people are full of prejudice, because there are a lot of people who think that the persons that have this disease, they will transmit it.* (I24)
> *It was a tremendous shock, I even thought about committing suicide when I was hospitalized, I got really depressed, I didn't want anyone to visit me, just my mother.* (I19)
> *It's hard to overcome this, at the beginning, I despaired, I cried, I wanted to do something stupid.* (I22)

> *It's horrible to accept, it was very hard*. (I24)
> *This one is the worst of all, I felt shattered, because I was paralyzed, I was scared*. (I28)
> *I was so sad, I didn't even think, I thought about dying right away*. (I4)
> *I was very weak, I even went through some psychologists, but I don't have this disease, the exams say I do, but I think I don't have it*. (I7)
> *It meant death, I thought I was going to die, I didn't want anything else*. (I18)
> *My life is over, you are well, suddenly you find out you have it.* (I22)

Other meanings present in the social representation of the group expressed negative feelings, such as sadness and fear, resulting from other contents very present in the representations since the beginning of the epidemic, such as death and the stigma on the person living with the virus.

> *It's sad, for a lot of things it's sad, but it's a disease that I think hurts, because a lot of people turn their backs, a very ugly disease*. (I7)
> *A disease that had this stigma of death.* (I12)
> *The disease is really ugly, I stayed at the time of death, there are things I still remember*. (I17)
> *I was very scared, I think that HIV is a very serious thing, a thing that kills, I don't like to know too much about it.* (I18)
> *Horrible, as soon as when we learn we have it, it's very sad, it's even hard to explain. Because you only see death in your head, that was the first thing I asked when the physician said, when he gave me the test results, we just think we're going to die.* (E24)

However, still in the central nucleus (Box 1), positive attributes regarding the naturalization of the disease are observed, considering it a chronic condition, present in the expression **normal disease**, reinforced by the expectation of the emergence of a cure for the disease, expressed by the term **cure** by the reference to treatment, present in the first periphery in the terms **medicines, care, treatment and life/living** and, in the second, in the term **I live a normal life**.

The peripheral elements showed polarity present in the analyzed representation, on the one hand reinforcing the negativity of HIV/AIDS with the word **discretion**, which translates the concealment of the disease as a way of avoiding prejudice; on the other hand, it corroborates positive contents present in the central nucleus, through the terms **medicines, care** and **treatment** that reflect important and necessary health care for survival, in addition to the words **life/living**, **God** and **I live a normal life** that express hope in life, with the support of spirituality. In addition, the words **prevention** and

condom were also observed, characterizing a dimension of knowledge related to protection against infection and the words **children** and **family**, which result from the support that is essential for coping with the disease.

> *A normal life, for me, taking the medicines correctly, I have a normal life.* (I4)
> *I think that what I do, besides the medication that helps a lot, I think it's correct, but I have a good diet, I practice sports, I play soccer with my colleagues, I go for a walk*. (I8)
> *I believe that in order to live with the HIV-positive virus, I need to have health, strength to work and my family by my side, giving me more support, that's what I need*. (I11)
> *What is vital for me is treatment and using condoms.* (I21)
> *The person has to seek treatment, take care of themselves, take the medication*. (I24)
> *Living with HIV today means living more carefully, taking care of everything, worrying about always eating, worrying about always taking the medicine.* (I26)
> *After I found out it became normal, I kept following life the way it is and asking God not to go too soon, normal like a normal person, just treating myself.* (I27)

Unlike the scenario experienced by many people infected throughout the HIV/AIDS epidemic, it is currently observed that the approach to the object, in this case HIV, and the strategies and policies of care for this population have led to a re-signification of the living with HIV or AIDS. This has been promoting changes in representation and, therefore, it is possible to perceive in this context the presence of contents related to a normal life and normal disease.

> *Nowadays, I think it's normal.* (I2)
> *Normal life, still normal, I also only remember that I have it when I come here*. (I15)
> *Normal, it became normal, I live normal.* (I23)
> *I try to have a normal life, do what I used to do, my activities.* (I24)
> *For those who ask me I say, I have no problem with that, not least because today I think it's normal*. (I25)
> *Today, to think that living with HIV is living normal, for me, it is as if it were just a daily task of care*. (I26)

Based on the analysis of the results, concepts and feelings of people regarding the serological reality were observed. It was noticed that representations focused on prejudice and death can be associated with the historical scenario of the disease, such as stigma, discrimination, the dreaded disease that, even linked to the beginning of the epidemic, is present in world society. Also, HIV was identified as a normal disease and this link, which was present in several speeches, may be linked to other representations evoked, such as treatment, medicine, care, living, which may have been built through living with the patient. HIV, that is, built empowerment.

Discussion

In view of the divergent dimensions in the central core, when presenting elements such as prejudice, death and normal disease, it is emphasized that any change in the central core of the representation causes a complete transformation of it, in this way, the identification of the central core allows a comparison study that, when identifying representations organized around two different central cores will result in two different representations. This is because “representations are at the same time stable and mobile, rigid and flexible”.[13:77]

It can be said that the term 'prejudice' was immediately evoked because it was directly linked to the stigmatization of the disease, which emerged in the 1980s, but which still prevails today and causes harm to those living with the virus, making the process of acceptance and coping with seropositivity difficult.[14] Study presents prejudice as a likely centralizer and organizer of social representation about HIV/Aids, corroborating the fact that misinformation is a strengthening aspect of this prejudice in society.[15] In another study with people living with HIV, the term prejudice was located on the first periphery of the structural analysis, but, in the analysis of similarity, this lexicon was considered, by hypothesis, as belonging to the central nucleus of the representation of AIDS, due to the amount of connections and strong ties established with other terms present in representation.[16]

Thus, prejudice is a meaning present in the way HIV and AIDS are constructed. It is noteworthy that society often still blames people for having acquired the disease, motivating the emergence of negative feelings of sadness.[17]

Feelings of sadness and fear are associated with the meaning of death present in this representation, as a result that is similar to another research carried out with people living with HIV/AIDS, in which the centrality of the terms fear, death and sadness was identified.[18] Likewise, in another study, the terms fear and death also had an indication of centrality, while the word sadness appeared in the contrast zone.[16]

The image of death is present at the time of diagnosis, in which the positive result means a fatal sentence, constituting a critical and significant moment, characterized by negative feelings, such as fear, sadness, terror, surprise, disbelief, injustice and shame. This discourse, in addition to coming from the social representations created since the emergence of AIDS, reflects the fragmented information in relation to the stages of infection and installation of the disease.[14]

Suffering seems to be closely related to the stigmas of the disease, often motivating the patient to deny his own health problem, change in behavior or even the loss of the will to live; on the other hand, there are patients who were not weakened by the seropositive diagnosis, adopting coping strategies.[19-20]

However, the evidence of different representational contents deserves attention, since HIV/AIDS is also represented as a normal disease, referring to the idea of normality, of a healthy life or with few diseases, permeated by the satisfaction of enjoying good health, despite having chronic disease. This notion is associated with combined antiretroviral therapy, consolidating the perception of a normal life, since with adherence, it is possible to ensure quality and longer life expectancy.[21]

It is noteworthy that despite the diversity of feelings, especially after diagnosis, the term normal disease is present, because when people experience the HIV health-disease process and empower themselves with knowledge about the disease, it is common for them to have a new look about the reality experienced, realizing that in addition to being alive, they can live with quality.[22] At the same time, a study points out that people living with the virus can live well and have a normal life, expressing the naturalization of the virus and the disease.[23]

The concept of normality attributed to AIDS originates from information from health services and from everyday observations, comparing it to chronic diseases, such as hypertension and diabetes, in which people will live undergoing treatment, using medication and having to adopt care for continuity of life.

The other elements of the representation constitute the peripheral system, which involves contradiction and is susceptible to possible alterations. Therefore, it can be said that the transformation of representation begins through changes in the elements of the peripheral system, resulting in mobility, flexibility and individualized expression of social representations.[24] In addition, the peripheral system allows adaptation, differentiation based on what was lived and integration of everyday experiences.[13]

In this way, it was found that the elements medicine, care, treatment and life/living, which made up the first periphery, complement the element “normal disease”, from the central nucleus, and indicate behaviors and practices recommended or adopted by the group, necessary for the maintenance of health and, consequently, of life itself. In addition, daily practices were identified in the contrasting and peripheral elements, such as **fight, prevention, discretion, God, I live a normal life, condom, children** and **family**, demonstrating ways of dealing with the virus and the disease to have a normal life, despite the difficulties, which may occur through coping strategies that can minimize suffering and adapt to the condition of HIV seropositivity.

Treatment is a fundamental form of care for those who live with the virus and make use of antiretroviral medications, and services need to welcome patients and provide comprehensive and humanized care, in order to ensure that care is efficient and patient-centered.[25] For this, the health system needs constant adaptations to guarantee the access and the integrality of the care so desired and fundamental for the articulation between professionals, users and health services, allowing to deal with affective and social issues, previously ignored.[26] In this sense, health policies aimed at the promotion and prevention of HIV are necessary, and it is up to the nursing and health professionals to make efforts so that actions are carried out satisfactorily.

Thus, the practice of using condoms, consistently and correctly, is effective in preventing sexually transmitted HIV infections, being considered a component of a comprehensive approach to HIV prevention.[27]

Nevertheless, the peripheral system is an essential element in the identification of ongoing transformations, and may be a potential indicator of future changes in representation, an indisputable symptom of an evolution in situations in which the representation is in the process of transformation.[15] Thus, it is proposed that the peripheral system of the analyzed representation presents elements that integrate characteristics about HIV/AIDS focused on the idea of chronic disease, pointing to a process of representational change underway in the studied group.

The research presented as a limitation the fact that most of the participants presented a profile of adults with extremes of age, which prevents the recognition of subgroups, in addition to having been constituted from a convenience sample, preventing the generalization of the results.

Through knowledge about the social representations of HIV and AIDS, this study seeks to contribute to the scientific community, especially professionals working in outpatient services, helping to design more effective care directed to the most impactful aspects of living with the virus and the disease, which may favor a better prognosis and contribute to the improvement or maintenance of quality of life of these people.

Conclusion

Several contents and dimensions were identified that are part of the social representation of AIDS for people living with HIV. Among the contents that organized the group's social thinking, elements related to social memory, attitudes, knowledge, images and affections stood out. The representational contents of HIV/AIDS following the representations among the group of people living with HIV were observed, since the beginning of the AIDS epidemic, due to the devastating social impact. On the other hand, references to a normal disease were found, which may be supported by the transformations that have taken place over more than three decades of the epidemic, due to the effectiveness of antiretroviral treatment and other factors associated with health care for this group.

Despite the presence of archaic elements present in the first representations of AIDS, this study demonstrates the existence of a process of change being operated in the social representations, probably as a consequence of living with the disease, through elements that characterize the adaptation to the evolution of the syndrome. and new ways of dealing with it. This change reflects the evolution of the epidemic that incorporates positive elements that translate a new concept, with perspectives of a better life, of constant overcoming the difficulties imposed by the disease.

References

1. Joint United Nations Programme on HIV/AIDS. Estatísticas [Internet]. 2021 [acesso 2021 mar 02]. Disponível em: https://unaids.org.br/estatisticas/

2. Brasil. Ministério da Saúde. Boletim Epidemiológico - HIV Aids [Internet]. 2020 [acesso 2021

mar 21]. Disponível em: http://www.aids.gov.br/pt-br/pub/2020/boletim-epidemiologico-hivaids-2020

3. Jesus GJD, Oliveira LBD, Caliari JDS, Queiroz AAFL, Gir E, Reis RK Difficulties of living with HIV/Aids: Obstacles to quality of life. Acta Paulista de Enfermagem. 2017;30(3):301-307. doi: https://doi.org/10.1590/1982-0194201700046

4. Bain LE, Tarkang EE, Ebuenyi ID, Kamadjeu R. The HIV/AIDS pandemic will not end by the year 2030 in low and middle income countries. The Pan African medical jornal. 2019;32:67. doi: 10.11604/pamj.2019.32.67.17580

5. Angelim RCM, Brandão BMGM, Oliveira DC, Abrão FMS. Public policies awareness toward the AIDS combat under the perspective of health professionals. Rev. pesqui. cuid. fundam.(Online). 2018; 913-918. doi: https://doi.org/10.9789/2175-5361.2018.v10i4.913-918.

6. Jodelet D. Representações sociais um domínio em expansão. In: D. Jodelet (Org.). As representações sociais. Rio de Janeiro: EDUERJ, 2001.

7. Oliveira DC, Gomes AMT, Marques SC, Penna LHG, Sá CP, Wolter RMCP, et al. As Transformações do Cuidado de Saúde e Enfermagem em Tempos de AIDS: estrutura ambulatorial, representações sociais e memórias de enfermeiros e profissionais de saúde no Brasil. Projeto de Pesquisa. Rio de Janeiro; 2009.

8. Ferreira SES, Brum JLR. As representações sociais e suas contribuições no campo da saúde. Rev Gaúch Enferm [Internet]. 2000 [acesso 2020 mar 02];20(esp.):5-14. Disponível em: https://seer.ufrgs.br/RevistaGauchadeEnfermagem/article/view/4323/2282

9. Moscovici S. Representações sociais: investigações em psicologia social. 11ª ed. Petrópolis (RJ): Vozes; 2017.

10. Bertoni LM, Galinkin AL. Teoria e métodos em representações sociais. In: Mororó LP, Couto MES, Assis RAM, orgs. Notas teórico-metodológicas de pesquisas em educação: concepções e trajetórias [online]. Ilhéus, BA: EDITUS, 2017, pp. 101-122. doi: 10.7476/9788574554938.005

11. Gomes AMT, Silva EMP, Oliveira DC. Social representations of AIDS and their quotidian interfaces for people living with HIV. Rev. Latino-Am. Enfermagem. 2011;19(3). doi: https://doi.org/10.1590/S0104-11692011000300006

12. Souza MAR, Wall ML, Thuler ACMC, Lowen IMV, Peres AM. The use of IRAMUTEQ software for data analysis in qualitative research. Rev Esc Enferm USP. 2018;52:e03353. doi: https://doi.org/10.1590/S1980-220X2017015003353

13. Abric JC. L'organisation interne des representations sociales: système central et système périphérique. In C. Guimelli (Org.). Structures et transformations des Representations Sociales. Neuchâtel: Delachaux et Niestlé. 1994.

14. Lobo ALDSF, Santos AAP, Pinto LMTR, Rodrigues STC, Barros LJD, Lima MGT. Women social representations in face to HIV diagnosis disclosure. Rev Fun Care Online. 2018;10(2):334-342. doi: http://dx.doi.org/10.9789/2175-5361.2018.v10i2.334-342

15. Oliveira DC. Construction and transformation of social representations of AIDS and implications for health care. Rev Latino-Am Enfermagem. 2013;21(spe):276-86. doi: https://doi.org/10.1590/S0104-11692013000700034

16. Souza IS. Representações sociais da aids: estudo com pessoas vivendo com HIV atendidas em unidades da rede de atenção primária em saúde do município do Rio de Janeiro. 144f. 2020. Dissertação (Mestrado em Enfermagem). Faculdade de Enfermagem da Universidade do Estado do Rio de Janeiro. Rio de janeiro.

17. Moreira AS, França Junior I, Jacob M, Cabral A, Martirani LA. Commensal meetings strategies regarding youth orphaned by HIV/AIDS in São Paulo, SP, Brazil. Interface Comun Saúde Educ. 2017;22(64):141-52. doi: https://doi.org/10.1590/1807-57622016.0425

18. Bezerra EO, Pereira MLD, Maranhão TA, Monteiro PV, Brito GCB, Chaves ACP et al. Structural analysis of social representations on aids among people living with human immunodeficiency virus. Texto & Contexto Enferm. 2018;27(2):e6200015. doi: https://doi.org/10.1590/0104-070720180006200015

19. Angelim RCM, Brandão BMGM, Freire DA, Abrão FMS. Processo de morte/morrer de pessoas com HIV/AIDS: perspectivas de enfermeiros. Rev Cuid. 2017;8(3):1758-66. doi: http://dx.doi.org/10.15649/cuidarte.v8i3.414

20. Góis ARS, Brandão BMGM, Oliveira RC, Costa SFG, Oliveira DC, Abrão FMS. Death/dying of people with HIV: from the nursing point of view. Revista de Enfermagem UFPE on line. 2018;12(12): 3337-43. doi: https://doi.org/10.5205/1981-8963-v12i12a236255p3337-3336-2018

21. Araújo SNOD, Nascimento VC, Santos FKD, Marques SC, Oliveira DCD. Representações sociais da terapia antirretroviral para pessoas vivendo com HIV. Rev. enferm. UFSM. 2021;11(e54):1-18. doi: 10.5902/2179769263378

22. Brandão BMGM, Angelim RCM, Marques SC, Oliveira DC, Oliveira RC, Abrão FMS. Social representations of the elderly about HIV/AIDS. Rev. Bras. Enferm. 2019;72(5):1349-55. doi: https://doi.org/10.1590/0034-7167-2018-0296

23. Domingues JP, Oliveira DC, Marques SC. Quality of life social representations of people living with HIV/AIDS. Texto & Contexto Enferm. 2018;27(2):e1460017. doi: https://doi.org/10.1590/0104-070720180001460017

24. Magalhães FC. Representações sociais de futuros docentes sobre a Teoria da Evolução darwinista. Revista de Educação Pública. 2018;27(66):839-857. doi: https://doi.org/10.29286/rep.v27i66.4286

25. Prust ML, Banda CK, Callahan K, Nyirenda R, Chimbwandira F, Kalua T et al. Patient and health worker experiences of differentiated models of care for stable HIV patients in Malawi: A qualitative study. PLos ONE. 2018;13(7):e0196498. doi: 10.1371/journal.pone.0196498

26. Silva CD, Júnior CAOM, Inada JF. Psicologia Social, Representações Sociais e AIDS. Revista de Ensino, Educação e Ciências Humanas. 2017;18(4):458-463. doi: https://doi.org/10.17921/2447-8733.2020v21n1p2-7

27. Koff A, Goldberg C, Ogbuagu O. Condomless sex and HIV transmission among serodifferent couples: current evidence and recommendations. Ann Med. 2017;49(6):534-544. doi: 10.1080/07853890.2017.1320423

Promotion: Coordination for the Improvement of Higher Education Personnel (CAPES).

Authorship Contributions

1 – Rebeca Coelho de Moura Angelim
Corresponding Author
Nurse, PhD. E-mail: rebecaangelim@hotmail.com
Conception, development of the research, writing of the manuscript, review and approval of the

final version.

2 – Sérgio Corrêa Marques
Nurse, PhD. E-mail: sergiocmarques@uol.com.br
Writing of the manuscript, review and approval of the final version.

3 – Denize Cristina de Oliveira
Nurse, PhD. E-mail: dcouerj@gmail.com
Review and approval of the final version.

4 – Regina Célia de Oliveira
Nurse, PhD. E-mail: regina.oliveira@upe.br
Review and approval of the final version.

5 – Daniela de Aquino Freire
Nurse, Master's Degree. E-mail: daniela_3439@hotmail.com
Review and approval of the final version.

6 – Fátima Maria da Silva Abrão
Nurse, PhD. E-mail: abraofatima@gmail.com
Review and approval of the final version.

Chief Scientific Editor: Cristiane Cardoso de Paula
Associate Editor: Alexa Pupiara Flores Coelho Centenaro

How to cite this article

Angelim RCM, Marques SC, Oliveira DC, Oliveira RC, Freire DA, Abrão FMS. Social representations of the Human Immunodeficiency Virus among HIV-positive adults. Rev. Enferm. UFSM. 2022 [Accessed on: Year Month Day]; vol.12 e39: 1-18. DOI: https://doi.org/10.5902/2179769268006